



HIV/AIDS STIGMA:

THEORY, REALITY, AND RESPONSE



HIV/AIDS BUREAU

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HIV/AIDS STIGMA: THEORY, REALITY, AND RESPONSE

Edited by Joan Holloway, Richard Seaton, and Jeff Crowley

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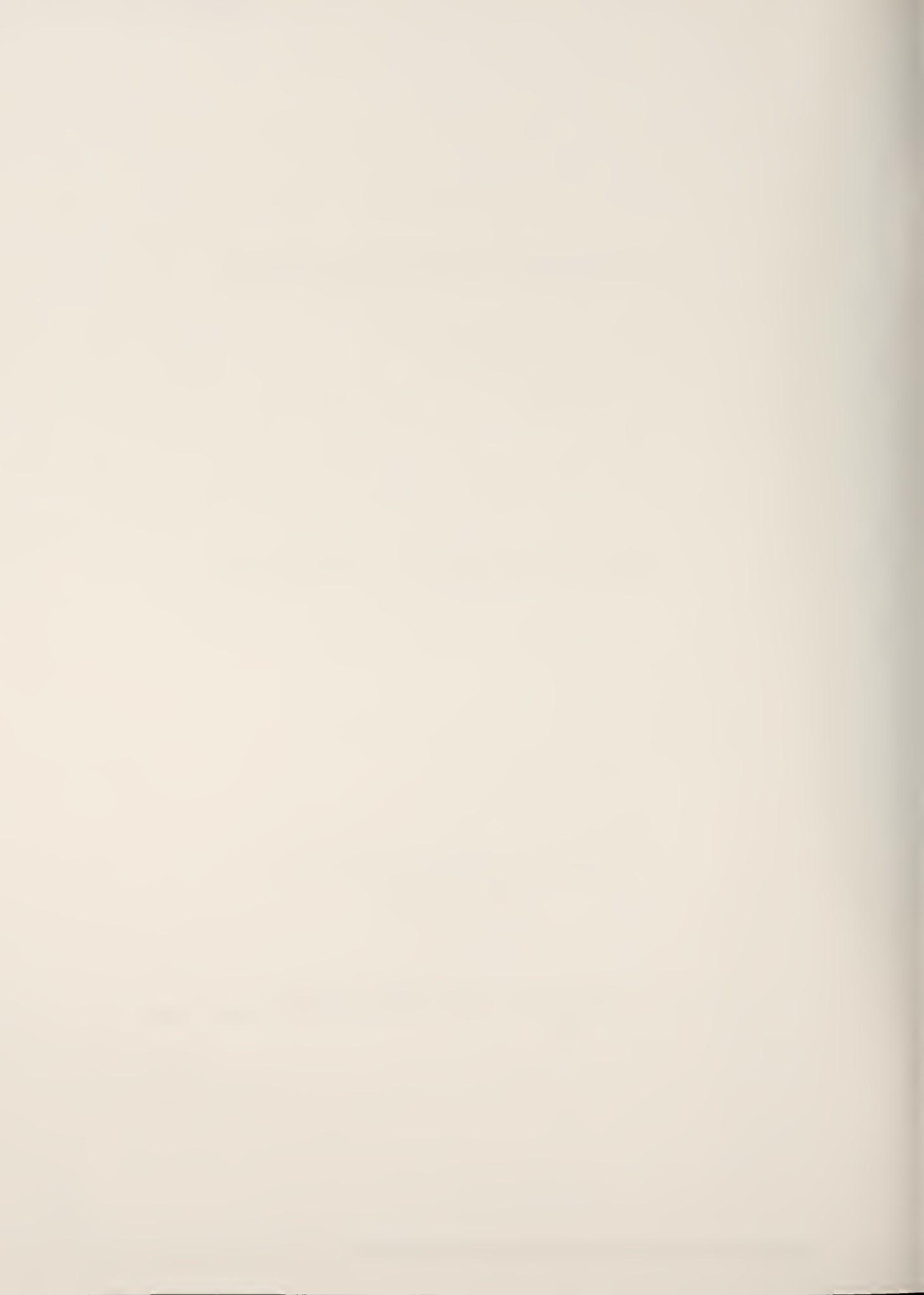
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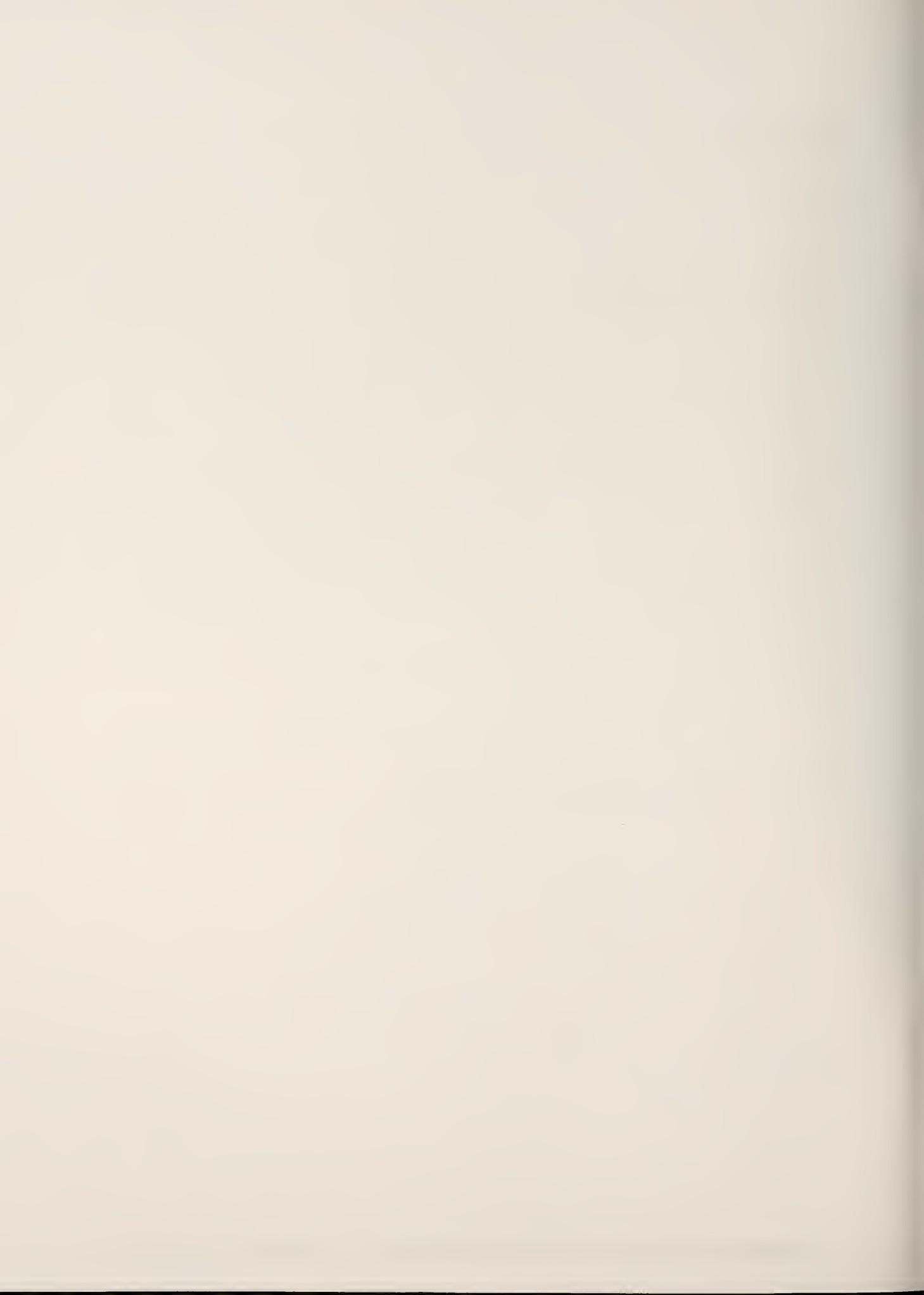




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INTRODUCTION

HIV/AIDS stigma is an extremely powerful force in American society. Negative attitudes and perceptions about HIV/AIDS and the populations the disease disproportionately affects can be catastrophic. Stigma results in loss of employment and housing opportunities. It can cause violence. The mere mention of the word “AIDS” can result in total ostracism from one’s family and social networks. It is little wonder, then, that HIV/AIDS stigma has been documented in the literature to result in delays in seeking HIV counseling and testing and care.

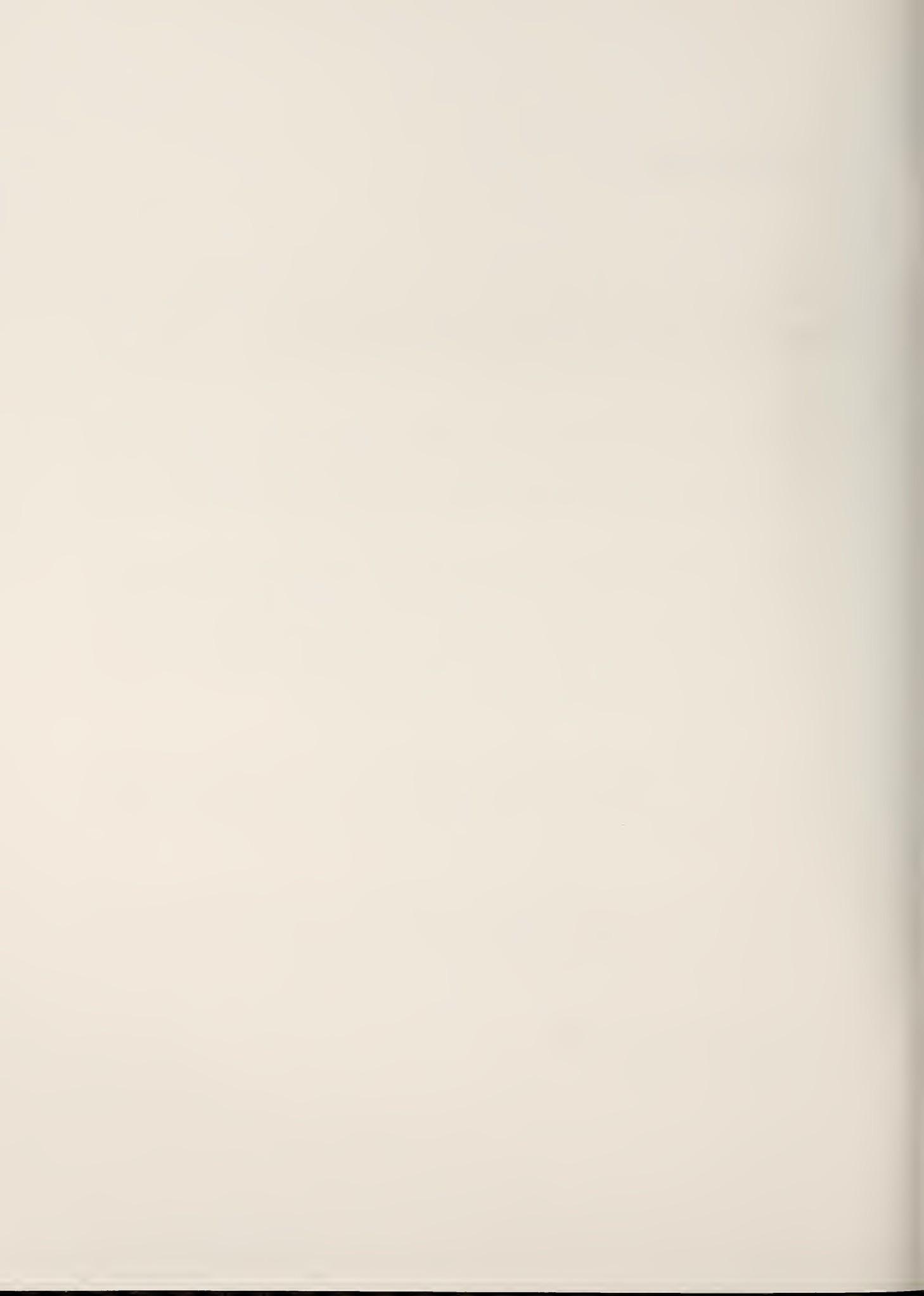
The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) administers the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, which provides care and services to under-insured and underserved people living with HIV/AIDS who have nowhere else to turn. Today, CARE Act funds are reaching underserved communities across the country, where providers are serving more than half a million people.

To enhance the quality of care and to improve productivity and efficiency of CARE Act–funded programs, HAB provides technical assistance services to CARE Act grantees and providers. We have given particular attention to HIV/AIDS stigma over the past 18 months. In particular, we conducted and disseminated a literature review and devoted an entire issue of our technical assistance newsletter, *HRSA CAREAction*, to the topic. Both of these publications are available on the Web at www.hab.hrsa.gov/publications. We have also conducted two community consultations on HIV/AIDS stigma: one in Atlanta, in collaboration with the Centers for Disease Control and Prevention, and another in Washington, DC.

The articles that form this compendium are based on presentations made at the meeting in Washington. They represent some of the most advanced research and thought on a topic that, 25 years after the emergence of AIDS in the United States, undeniably continues to play a role in perpetuating HIV disease. Together, these articles provide a detailed exploration of HIV/AIDS stigma, its manifestations and results, and how it can be mitigated.

HAB salutes the dedication of the HIV/AIDS service community and honors the community's commitment to addressing barriers to services encountered by so many people. It is hoped that this volume will help providers find increasingly effective means to address stigma so that people living with HIV/AIDS can reap the benefits of a prevention and care system that has never had more to offer.

Deborah Parham Hopson, Ph.D., R.N.
Rear Admiral, USPHS
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BACKGROUND

ON HIV/AIDS STIGMA

Background on HIV/AIDS Stigma

PREPARED BY JEFFREY S. CROWLEY AND FRENK GUNI

The Health Policy Institute, Georgetown University, working under contract with the U.S. Department of Health and Human Services' Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB) conducted a 2-day community consultation in Washington, DC, May 22–23, 2004, on promoting the leadership of people living with HIV/AIDS in responding to HIV/AIDS stigma. Participants included a range of educators, advocates, and researchers working to address HIV/AIDS stigma in the United States and throughout the world. The consultation provided an opportunity for HRSA to learn more about the scope of HIV/AIDS stigma and the many ways that stigma inhibits HRSA's efforts to respond to the HIV pandemic. Information and insights gained by HRSA, along with the specific policy and programmatic recommendations received, will be used by HRSA to consider new approaches to addressing HIV/AIDS stigma and to incorporate stigma reduction activities as part of its ongoing programs through the Ryan White CARE Act. The following is background information provided to meeting participants in order to lay the groundwork and provide a context for the group discussion on strategies for moving forward to develop more effective HIV/AIDS stigma reduction initiatives.

What is stigma?

Stigma has many definitions and is closely linked to different but related concepts of discrimination and shame. Although many definitions of stigma exist, Ervins Goffman, who is widely credited with developing a framework for the study of stigma, holds that stigma is “an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society.” Following from this definition, stigmatization is “a dynamic process that arises from the perception that there has been a violation of shared attitudes, beliefs, and values.”¹

The fear of stigma leads to silence, and when it comes to fighting AIDS, silence is death. It suppresses public discussion about AIDS, and deters people from finding out whether they are infected. It can cause people—whether a mother breastfeeding her child or a sexual partner reluctant to disclose their HIV status—to risk transmitting HIV rather than attract suspicion that they might be infected.

Kofi Annan, Secretary General of the United Nations, on World AIDS Day, December 2002.

Shame has been defined as “a negative emotion elicited when a person experiences failure in relation to personal or social standards, feels responsible for this failure, and believes that the failure reflects self-inadequacy rather than inappropriate behavior.” Therefore, shame can be viewed as an internalized response to stigma.²

Discrimination is “an identifiable action or series of actions, while stigma is the expression of social attitudes that define how some groups experience life in their community.”³ Stigma is closely linked to acts of active discrimination. However, whereas discrimination commonly affects relatively few individuals who directly experience discrimination, stigma is far more pervasive, affecting not only directly affected individuals, but also persons associated with the individual, such as family members and friends, health care workers, and other members of the same community. Stigma of persons not directly part of a stigmatized group is sometimes referred to as “secondary stigma.”

Researchers have described stigma in a variety of ways. One construct is to distinguish between felt stigma (or perceived stigma) and enacted stigma. In this case, felt stigma can be seen as a survival strategy to limit the occurrence of enacted stigma. Felt stigma could take the form of someone denying his or her HIV status to avoid social isolation. Enacted stigma refers to the real experience of discrimination.

What is the impact of HIV stigma?

HIV stigma is widespread in the United States and around the world. Some people have argued that stigma is the single largest barrier to generating a stronger response to the HIV pandemic. It is undoubtedly a huge problem that inhibits effective responses to HIV at the individual, community, and societal levels.

Terje Anderson and others have stated that HIV presents the perfect conditions for a stigmatized condition, citing four factors:^{4,5}

1. The person with the disease is perceived as responsible for having it.
 2. The disease is viewed as fatal or degenerative.
 3. The condition is viewed as contagious or likely to result in the infection of others.
 4. The condition produces physical changes that are visible to others and unpleasant to look at.

The International Center for Research on Women (ICRW), in describing initial findings of an ongoing study to investigate the causes, manifestations, and consequences of HIV/AIDS-related stigma in Ethiopia, Tanzania, and Zambia echoes Anderson in stating that, “through stigma, society often blames infected people for being ill and justifies discriminatory acts against them while asserting the innocence and health of those who stigmatize.”⁶

Anderson has described a “hierarchy of guilt,” wherein persons perceived to be the least responsible for their HIV status, such as children who become infected through tainted blood products, receive the most favorable responses from society. Next are those who were infected through heterosexual sex, with most sympathy going to persons who mistakenly believed they were in monogamous relationships. He says, “in every measurement, gay men and injection drug users sit at the bottom of the hierarchy.”⁷

Gloria Casale and Julie Pulerwitz have described the gender dynamic of HIV stigma in many developing countries. Casale stated that "women who are HIV-positive or who are perceived to be positive are subject to discriminatory treatment, abandoned and shunned by their families and communities, dismissed from employment, assaulted and even killed."⁸ In describing a global HIV/AIDS operations research project conducted by Horizons/Population Council, Pulerwitz reported findings of a study of HIV/AIDS stigma and discrimination in a workplace program in South Africa. Although key findings included that many workers fear stigma more than discrimination in the workplace and that the main manifestation of stigma is social isolation

From “AIDS-Related Stigma: Background Discussion”

[Referring to a “hierarchy of guilt”] [A] graphic illustration of how this phenomenon can work was witnessed by the author of this article while working as an AIDS service provider in Vermont in the early 1990s. A small town of less than 2,500 people in a rural area of the State rallied around an HIV+ woman whose young child died of the disease. When word got out about her diagnosis, nearly the entire town turned out for a day of fundraising activities and festivities organized by a local church to support the woman and her family. The event was widely reported in the Vermont media of the time as an example of a compassionate community response to the epidemic.

However, in the same town at the same time, a male couple who were both HIV+ reported being widely shunned and made to feel unwelcome when speculation about their HIV status circulated among the same people who had supported the woman and her family. Negative comments and petty vandalism with a focus on sexual orientation became commonplace, and the couple experienced what they felt to be an overtly hostile existence.

Source: Anderson T. *AIDS-related stigma: Background discussion*. Washington, DC: National Association of People With AIDS.

and ridicule, she also reported that women fear stigma more than men do. Pulerwitz quoted a male worker who said, “This disease is associated with misbehavior. People would think the woman was sleeping around. They never blame a man. However, we are responsible for this. We have brought this thing home.”⁹

Lisanne Brown and colleagues have cited a number of ways that HIV stigma manifests itself. Research has shown that AIDS stigma negatively affects HIV test-seeking behavior, willingness to disclose HIV status, health-seeking behavior, quality of health care received, and social support solicited and received. They assert, “For some individuals, not knowing one’s HIV status is far preferable to being tested.” They have documented the negative effects of stigma on caregivers and health care workers, noting that individuals are often stigmatized just for caring for people living with HIV/AIDS.¹⁰

Gregory M. Herek and colleagues conducted a review of HIV-related stigma and knowledge in the United States from 1991 to 1999. They found that although public knowledge has increased, a great deal of HIV-related stigma persists. They reported that, on the hopeful side, “overt expressions of stigma appear to have declined over the 1990s”: In 1999, fewer than 1 in 5 adults still supported such measures as quarantining and public identification of people living with HIV/AIDS. Nevertheless, they also reported that in 1999, 1 in 5 people surveyed still feared people living with HIV/AIDS, and 1 in 6 expressed disgust or support for the public naming of people living with HIV/AIDS. They also explained that these attitudes translate into behavior that can lead to discrimination. For example, nearly one-third of respondents said that they would avoid shopping at a neighborhood grocery store whose owner had AIDS. They also reported that “the proportion of adults believing that a person infected with HIV through sex or drug use deserved to have AIDS increased over the decade, peaking in 1997.” Another important finding of this survey was that although respondents understood how HIV is transmitted, they were less clear about how it is *not* transmitted.¹¹

An interesting observation can be made by looking at the sample used by Herek. In 1997, in a sample of 1,309 individuals, 55.3 percent were female and 79 percent were non-Hispanic white. The median age was 44, the median annual income was between \$40,000 and \$50,000, and the median education level was 1 to 2 years of college. Similarly, the 1999 sample, with 669 individuals, was 55 percent female and 82 percent non-Hispanic white. The median age was 45, the median annual income was between \$40,000 and \$50,000, and the median education level was some college. These samples consisted of fairly well educated middle class people—people who could be expected to be better educated about HIV/AIDS than others. When compared with communities of color or economically disadvantaged communities, these populations may also be more isolated from direct interactions with people living with HIV or more removed from the impact of the HIV epidemic on the community.

What are lessons learned from HIV stigma research?

When turning to the question of what has been learned from research, an important observation is the extent to which HIV-related stigma has not been extensively studied.

Brown and colleagues reviewed 22 studies that test a variety of interventions to decrease HIV stigma in developed and developing countries. The majority of these studies were conducted in the United States. The authors reported that a major shortcoming of these studies is that the majority present hypothetical encounters with people living with HIV/AIDS, which does not ensure that respondents will be tolerant to HIV-positive individuals in actual encounters. They also reported that a majority of the interventions were tested among small samples of select populations, thereby calling into question the generalizability of the findings.

Another key finding of their analysis is that there was a tremendous diversity in the measures used to assess stigma, and few studies assessed the long-term effect of anti-stigma interventions. In discussing the implications of their findings, Brown and colleagues stated, “We still know very little about what it takes to change attitudes in the long-term.” They also stated, “The studies reviewed here suggest that contact with [people living with HIV/AIDS] might be one of the most promising approaches, though it is clearly not sufficient without improved understanding about the disease (i.e., together with information approaches).”¹²

Pulerwitz’s study of stigma and discrimination among employees of the main South African power company highlighted the need to address stigma and discrimination together, but as discrete phenomena. Pulerwitz found that “non-discriminatory workplace HIV/AIDS policies can make workers feel relatively secure that they will not be fired from their jobs. Equally important, however, is to address social isolation and ridicule when developing stigma-reduction activities.” When workers were asked for examples of bad treatment faced by people living with HIV/AIDS, 73 percent of men and 65 percent of women reported social isolation. High percentages of men and women also said that people with HIV/AIDS faced rumors and gossip, rejection, and ejection from the home.

ICRW published preliminary findings of its three-country study of HIV-related stigma and discrimination in Africa. The authors identified six key themes emerging from the data analyzed to date. They found that people are unaware that their actions and attitudes are stigmatizing and explained this finding by citing respondents who talk about how important it is not to stigmatize or discriminate against people living with HIV/AIDS, saying they would never behave this way. But they also describe people living with HIV/AIDS as people who are promiscuous or immoral—or people who are being punished by God for their sins. ICRW says that language is central to how stigma is expressed. They cite the fact that discussing or naming

Six key themes are emerging from data analyzed to date:

1. People are largely unaware that their attitudes and actions are stigmatizing.
2. Language is central to how stigma is expressed.
3. Knowledge and fear interact in unexpected ways that allow stigma and discrimination to persist.
4. Sex, morality, shame, and blame are closely related to HIV-related stigma.
5. Disclosure of positive HIV status is advocated, but acknowledged as difficult and unusual.
6. Widespread care and support for people living with HIV/AIDS coexist with stigma and discrimination.

Source: Addressing HIV-related stigma and resulting discrimination in Africa: A three-country study in Ethiopia, Tanzania, and Zambia.

HIV/AIDS openly is uncommon. The authors state that “HIV/AIDS is often referred to as ‘that disease we learned about.’” ICRW says that knowledge and fear interact in unexpected ways. “In all three countries, there is a genuine fear that HIV is transmitted casually despite ‘knowing’ that it is not … even highly knowledgeable people have genuine fears and concerns about casual transmission and a belief that death is imminent once infected with HIV.”¹³

The ICRW findings include the observation that sex, morality, shame, and blame are closely related to HIV-related stigma. The authors stated that in all three countries, much of the stigmatizing and discriminatory behavior centers on the sexual transmission of HIV. For example, in Tanzania and Ethiopia, “respondents believe that the young are getting HIV because their sexual behavior is irresponsible, they do not listen to their elders, and they do not uphold traditions.”¹⁴ Another research finding is that disclosure of HIV-positive status is advocated, but acknowledged as difficult and unusual. The final key theme emerging from the ICRW research is that widespread care and support for people living with HIV/AIDS coexist with stigma and discrimination. The authors state that “although loving care and support [are] given, [they] can be accompanied by stigmatizing and discriminatory attitudes and behavior from caregivers (like blaming and scolding), even though they may not recognize it as such.”¹⁵

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⁶ International Center for Research on Women [ICRW]. *Addressing HIV-related stigma and resulting discrimination in Africa: A three-country study in Ethiopia, Tanzania, and Zambia.* 2002.

⁷ Anderson T. *AIDS-related stigma: Background discussion.* Washington, DC: National Association of People with AIDS.

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¹⁰ Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Educ Prev.* 2003;15(1):49-69, citing Byrd et al. 1999; King 1989; Malcolm et al. 1998; Muyinda et al. 1997; Raveis et al. 1998; Sowell et al. 1997; Cameron 2000; Gerbert et al. 1991; Kelly et al. 1987; Weinberger et al. 1992.

¹¹ Herek GM, Capitanio JP, Widaman, KF. HIV-related stigma and knowledge in the United States: Prevalence and trends, 1991-1999. *Am J Public Health.* 2003;92(3):371-7.

¹² Brown L, Macintyre K, Trujillo L. Interventions to reduce HIV/AIDS stigma: What have we learned? *AIDS Educ Prev.* 2003;15(1):49-69.

¹³ The International Center for Research on Women (ICRW). *Understanding HIV-related stigma and resulting discrimination in Sub-Saharan Africa: Emerging themes from early data collection in Ethiopia, Tanzania, and Zambia,* June 2002.

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- ¹⁵ ICRW. *Understanding HIV-related stigma and resulting discrimination in Sub-Saharan Africa: Emerging themes from early data collection in Ethiopia, Tanzania, and Zambia*, June 2002.

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EMERGING FINDINGS

AND IMPLICATIONS FOR INTERVENTIONS

Emerging Findings and Implications for Interventions From a Multiple-Country Research Study in Sub-Saharan Africa

LAURA NYBLADE AND KERRY MACQUARIE

Laura Nyblade, Ph.D., and Kerry MacQuarrie of the International Center for Research on Women (ICRW) discuss emerging findings and implications for interventions from a study of HIV/AIDS-related stigma and discrimination in three countries in Sub-Saharan Africa.

This is a summary of a presentation given by Laura Nyblade and Kerry MacQuarrie regarding findings from a study of HIV/AIDS-related stigma and discrimination in three countries in Sub-Saharan Africa. The research was led by ICRW in partnership with the Miz Hasab Research Center in Ethiopia, Muhimbili University College of the Health Sciences in Tanzania, and the Zambart Project and Kara Counseling and Training Trust in Zambia. Conducted from April 2001 to September 2003, the study was funded by the United States Agency for International Development through the CHANGE Project of the Academy for Educational Development. Additional information about ICRW is available online: www.icrw.org.

The project was initiated to disentangle the complex elements of stigma and to further the search for appropriate entry points for stigma interventions. These efforts are particularly urgent in the developing world because of the dearth of research about HIV stigma in developing countries, the barrier stigma poses for an effective response to HIV, and the rapidly expanding HIV epidemics being faced by many of those countries.

Study Design

The study focused on stigma at the community level. The research examined stigma at the individual level, within households, and more broadly within the community as well as within institutions (related to health, faith, education) serving those communities. In each country, an urban and a rural site were identified. Researchers employed a range of qualitative tools to understand stigma within each site and conducted cross-country comparisons.

Study Design

- + Community-based, comparative study
 - One rural and one urban site in each country
 - + Sub-Studies
 - Longitudinal study with people living with HIV/AIDS (Ethiopia, Tanzania)
 - Health care training facility (Tanzania)
 - Language and media content (Tanzania)
 - HIV and TB stigma content (Tanzania)
 - HIV and TB stigma household cohort study (Zambia)
 - Children and stigma (Zambia)
-

In addition to this comparative community-based research, researchers conducted a range of substudies to address issues of particular importance to each country.

The researchers adapted their approach to the study as it unfolded, taking lessons learned in one country to improve the study in the others. For example, one of the initial lessons came from Tanzania, where people struggled with ways to talk about stigma. The spoken language in Tanzania is Swahili, which at the time did not have a commonly recognized word for stigma. Since then, the word *Kunyanyapaa* has gained more recognition as meaning *stigma*. Because of this lack of vocabulary, the researchers engaged in a dialogue with community members that relied on pictures and story telling.

Emerging Themes

Based on the collective experience in Ethiopia, Tanzania, and Zambia, researchers have identified nine emerging themes, which were observed consistently across all three countries and across the study sites within each country:

1. Knowledge and fear interact in unexpected ways that allow stigma and discrimination to persist.
2. There is a disconnect between people's stated intentions not to stigmatize and their stigmatizing action—indicating a lack of awareness of their own stigmatizing and of their discriminatory attitudes, actions, and language.
3. Language is central to how stigma is expressed.
4. Public disclosure of positive HIV serostatus is advocated, but it is acknowledged as difficult and unusual.
5. Care and support for people living with HIV/AIDS (PLWHA) are widespread but coexist with stigma.
6. Poverty and stigma create a double burden for the poor, who have few resources with which to cope with the effects of stigma.
7. Sex, morality, shame, blame, and guilt are closely related to HIV/AIDS-related stigma
8. Women face more and often harsher stigma than men do, and they have fewer resources to cope with stigma.
9. Young people are blamed for HIV because they are perceived to frequently engage in "inappropriate" sexual behavior.

Critical Elements for Intervention

Through this research, three critical elements for intervention have emerged that are relevant to any intervention to reduce stigma, no matter the environment. They hold lessons that are applicable to stigma reduction efforts in the United States.

Create Awareness

The first step in interventions to address HIV/AIDS stigma is to create awareness and recognition about

- + the existence of stigma;
- + ways in which stigma is harmful to ourselves, our families, and our communities;
- + the need for individuals to take action to reduce stigma; and
- + the benefits of stigma interventions to ourselves, our families, and our communities.

Interventions must create awareness and recognition of the role everyone plays in creating or reducing stigma, and that there is a role for each of us. Individuals can play an active role in reducing stigma by

changing their attitudes, language, and behavior. Most people have good intentions not to stigmatize. Those good intentions provide a foundation on which to build stigma-reducing interventions.

Provide In-Depth Information

The second key step addresses the belief that HIV equals immediate disability and death, which fuels the perception that PLWHA are noncontributing members of society. To effectively reduce stigma, interventions must address those fears and misconceptions. That step relates to people's ongoing fear of casual transmission, despite longstanding educational programs. The presence of the fears in all three countries is startling. The research found that respondents have internalized core transmission and prevention messages they have heard but—because of the narrow focus of those messages—they have applied this information in ways that often result in stigma.

A classic example from all three countries is the fear of sitting next to someone on a bus who looks like he or she has AIDS. The obvious physical avoidance of the person is stigmatizing. The behavior stems from a fear of becoming infected with HIV if the bus crashes and there is blood. People know HIV is transmitted through blood, and they know it is a deadly virus. Therefore, they consider avoidance of the person on the bus to be a logical measure for preventing HIV.

Critical Elements for Intervention

- + Create awareness.
 - + Provide in-depth information.
 - + Provide safe spaces.

What they do not understand is that HIV is a relatively weak virus; that it does not survive outside the body for very long; and that blood flows out of the body, not into it—making this a very low risk situation. The community has assimilated the key messages of HIV prevention programs, and individuals have applied those messages to their own lives in a logical way in what they perceive as risky situations. What they lack is in-depth information that can help them accurately assess the actual risk of daily interactions and behaviors very clearly related to stigmatizing and discriminatory behavior.

Another example of the relationship between misinformation and stigmatizing fears arose during efforts by ICRW and its partners to address the prevention of mother-to-child transmission (PMTCT) of HIV. This work found that many community members, particularly men, doubted the usefulness of PMTCT programs because of their belief that during pregnancy the baby is fed directly by the mother's blood—that the mother's and baby's blood are one. Because they assume that if the mother is HIV infected, the baby has to be infected, they doubt that a pill is going to break that transmission link. This problem stems from an incomplete understanding of pregnancy, illustrating the need to move beyond our narrow educational messages.

ICRW research also shows how global communication allows people to gather bits and pieces of information—without gaining depth of knowledge—and apply this information to situations in their own lives. The

consequences can be potentially damaging, both in terms of stigma and the spread of HIV. For example, a trainee in Ethiopia explained that in his community some men believe that if you have HIV it is good to have sex with lots of people who are not infected, because every time an infected man ejaculates, he will give away a little bit of the virus in his body, therefore lowering his viral load. In this case, these men absorbed enough of the news about antiretroviral drugs to know that low viral loads are a good thing. But they lacked the depth of knowledge that would have dismissed the validity of the myths circulating in their community.

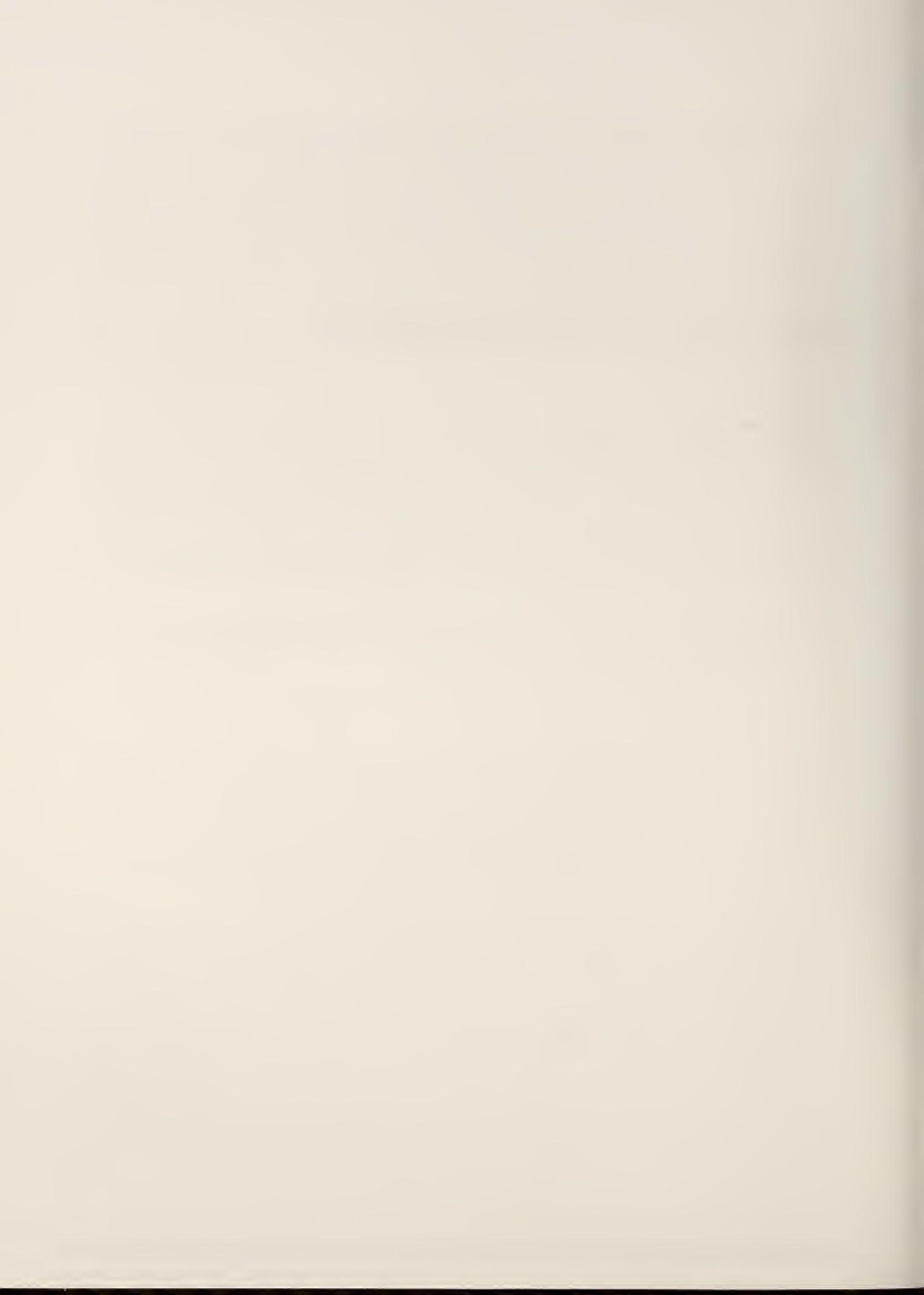
These examples show that bits of information have been incorporated—often in logical ways—with damaging consequences. They also illustrate the need to provide more comprehensive, current information in an ongoing and interactive way to keep up with the rapid advances and constantly changing information on HIV/AIDS.

Provide Safe Spaces

The third step, which is probably the most difficult, is to provide safe spaces to begin to explore the underlying issues and values that fuel the epidemic and the stigma that surrounds it. Those sensitive and often taboo issues include attitudes about appropriate sexual behavior (the most common method of transmission in the countries studied); social and economic inequities, particularly gender inequities; and fear of death. On the face of it, this might seem like an insurmountable challenge, but we found that in some communities, particularly in Zambia, the devastation wrought by AIDS has opened up the space and created the will to begin to grapple with those difficult issues.

All of these steps need to be addressed if we are to succeed in reducing stigma, enabling individuals to create and adopt nonstigmatizing principles, values, and behavior.







HOW STIGMA INHIBITS POSITIVE

RESPONSES TO THE HIV PANDEMIC

Stigma Mitigation Components in HIV/AIDS Programs

TERJE ANDERSON

Terje Anderson is executive director for the National Association of People With AIDS (NAPWA). In this article, he discusses how stigma impedes society's response to the HIV/AIDS epidemic, and he outlines key interventions for mitigating its effects.

Introduction

Since the beginning of the AIDS epidemic, stigma has been a critical issue, but its power is perhaps even greater than is often acknowledged. Stigma defines virtually every level of society's reaction to HIV/AIDS yet it often goes unnoticed and unchallenged. Stigma is in the air we breathe, and is internalized by everyone, whether they are HIV-positive or HIV-negative. Until stigma is named and challenged, little can be done to mitigate its effects.

There are many reasons why HIV/AIDS is so highly stigmatized. It is a disease that is commonly transmitted through sex or drug use—behaviors that society often demonizes. HIV is also a debilitating disease, with highly visible symptoms that can make people uncomfortable. Moreover, HIV is infectious, and even those who are educated about HIV transmission may harbor irrational fears of contagion. Finally, HIV is often viewed as a disease of “the other,” which enables a large part of society to believe “HIV/AIDS is not about me.” At the onset of the epidemic in the United States, for example, “the other” was the gay man or the injection drug user. Exacerbating HIV/AIDS stigma is a growing sense of anger and resentment toward people living with HIV/AIDS (PLWHA), both in the United States and around the world. PLWH/A may be perceived as somehow privileged by their serostatus because it gives them greater access to subsidized health care. This resentment stems from a concern that people with HIV in this country receive care through programs like Medicaid or the Ryan White CARE Act—while HIV-negative poor and uninsured people are left to fend for themselves.

Too often, in the past, stigma reduction has been likened to a model of enlightenment, in which those who know best intervene to correct the bad thoughts and actions of others. This approach sees the minds of people as empty vessels waiting to be filled with good ideas of intervention specialists and communications experts, instead of empowering communities through a participatory process that unleashes their own knowledge and experiences.

—A conceptual framework and basis for action: HIV/AIDS stigma and discrimination. UNAIDS, 2002.

The effects of stigma are damaging and impede our response to the AIDS epidemic. For example, stigma may make people less willing to adopt preventive behaviors. Stigma also hinders efforts to garner support from political leaders in the fight against HIV/AIDS because leaders who speak out about HIV/AIDS risk being painted with the same brush as people infected with the disease—just one example of how stigma makes people reluctant to be associated with PLWH/A.

Interventions to Mitigate Stigma

Three underlying assumptions should inform stigma-related programs:

1. Stigma is a complex and multilayered issue, and so the interventions to reduce it must be as well.
2. Efforts to combat HIV-related stigma cannot ignore related stigmas, such as those concerning race and ethnicity, sex and sexuality, gender, class, addiction, disease, and death.
3. Mitigation, not elimination, is the realistic short- to medium-term goal.

Today, many new stigma-specific interventions are being implemented and evaluated. However, the majority of activities currently in place that counter stigma are not stigma interventions per se. Instead, they are larger projects that have stigma mitigation components. The importance of these efforts is difficult to overstate as they provide the opportunity to reach large numbers of people and to address stigma in its many forms. Although some overlap exists, these interventions usually follow one of six strategies.

Provide Knowledge and Education to the Public

According to leading experts on HIV/AIDS stigma, including Gregory M. Herek, stigmatizing attitudes are strongly correlated with misinformation and irrational fears. Educating the public about HIV/AIDS is therefore an important step in confronting stigma. The power of public information campaigns was demonstrated in the 1980s when the Surgeon General mailed to every household in the United States a report outlining key facts about HIV transmission. Just a few years later, the percentage of Americans who believed they could contract HIV from casual contact (such as from mosquitoes or toilet seats) had declined dramatically. Unfortunately, Herek's research indicates a recent increase in the prevalence of misinformed and inaccurate beliefs about the disease. It is therefore important to go back to the basics and reeducate the public about HIV/AIDS.

Humanize the Stigmatized Population

Stigma thrives on the perception of “otherness.” Putting the public in contact with the HIV-positive population can help humanize PLWH/A and can make HIV a disease of “people like me” instead of a disease of “the other.” For example, speakers’ bureaus can facilitate visits to churches, schools, Rotary Club meetings, and offices so PLWH/A can tell their stories and talk about what it means to live with HIV. The media can also play an important role by bringing to light true stories about PLWH/A. For example, in the late 1980s Newsweek ran a very powerful issue containing individual portraits of people who had died of HIV/AIDS. Literally hundreds of people were profiled, representing a cross-section of America. Finally, celebrities who publicly disclose their HIV status can help mitigate stigma, in part because Americans often think about celebrities as if they were personal friends, neighbors, or peers.

Challenge the Social Acceptability of Stigma

Campaigns and materials can challenge the social acceptability of stigma and confront the social norms and attitudes that drive stigma and discrimination. Reverse stigma—or the stigmatization of people who hold stigmatizing views—has met with some success in the United States. In 1993, for example, American

Ways to Address HIV/AIDS-Related Stigma

Strategy	Rationale	Intervention
Provide knowledge and education to the public.	Increasing the public's basic knowledge about HIV/AIDS helps address the misinformation and fear that underlie stigma.	<ul style="list-style-type: none"> + Science-focused, school-based AIDS education + Public information programs, materials + Expert spokespeople + Community or peer-led population education activities + Workplace education programs
Humanize the stigmatized population.	Stigma thrives on the perception of "otherness." Putting the general public in contact with the HIV-positive population can help humanize them.	<ul style="list-style-type: none"> + HIV-positive speakers' bureau + HIV-positive people disclosing to family, friends, workplace, and community + UNAIDS workplace programs + HIV-positive spokespeople in the media + Media profiles of HIV-positive people, public service announcements, posters + Celebrities disclosing their HIV status + Fictional depictions of HIV-positive people + AIDS quilt
Challenge the social acceptability of stigma.	Campaigns and materials can change social norms and community attitudes that drive stigma and discrimination.	<ul style="list-style-type: none"> + Red ribbons, World AIDS Day campaigns, Balm in Gilead's Week of Prayer, gubernatorial or mayoral proclamations, Latino AIDS Awareness Day + Social marketing messages and materials (e.g., "My friend with AIDS is still my friend") + Explicit declarations of welcome from faith groups, businesses + Creation of community coalitions and alliances + Boycotts and tougher campaigns to "punish" those who discriminate + Family efforts (Mothers' Voices, PFLAG) + Needle-exchange programs + Provider training and sensitization + Media training and sensitization
Help people affected by stigma develop the tools to survive it—and combat it.	Help PLWH/A cope in a stigmatizing environment so they are less likely to internalize stigma and discrimination.	<ul style="list-style-type: none"> + Self-help and support groups + Microcredit schemes + Employment training + PLWH/A leadership training + PLWH/A involvement on planning and advisory bodies + Positive-only social activities and dating services + Activism

Ways to Address HIV/AIDS-Related Stigma

Strategy	Rationale	Intervention
Develop legal and regulatory responses to protect people from stigma and discrimination.	Stigma often manifests itself in discrimination. Through legal and regulatory efforts, we can create a more welcoming and safe environment for PLWH/A, sending a message of social inclusion and challenging the acceptability of stigma and discrimination.	<ul style="list-style-type: none"> + State and local antidiscrimination laws + Federal Americans with Disabilities Act + Workplace policies + International human rights agreements + Codes of practice + Medical confidentiality laws and policies
Provide effective HIV/AIDS care and treatment.	<p>Effective treatment challenges the fatalistic view of HIV/AIDS as inevitably degenerative. Treatment advances also allow PLWH/A to be—and to be viewed as—productive, contributing members of society, not as a burden on others.</p>	<p>Unfinished “agenda”</p> <ul style="list-style-type: none"> + U.S. travel and immigration restrictions + U.S. military, Peace Corps, foreign service restrictions + Prevention program content restrictions + State criminalization laws + Culture wars vs. public health + Public health messages and programs that isolate, blame, and stigmatize + Continued generalized discrimination based on race or ethnicity, sexual orientation, gender, addiction, nationality, incarceration history, age, sex, socioeconomic status + Community-based care and treatment programs + Ryan White CARE Act + Médecins Sans Frontières, other drug and care programs in the developing world

*Adapted from a presentation by Terje Anderson at the CDC/HRSA Consultation on HIV/AIDS-Related Stigma. Atlanta, GA, November 2003.

Airlines expelled a passenger with AIDS from a flight for failing to cover lesions on his face and for attaching an IV bag to his seat. The television captured a horrible scene in which airport police were dragging the man kicking and screaming from an airplane. The airline argued that he was removed because the crew wanted to ensure he was healthy enough to make the flight, and because airlines are required by law to ensure passengers are not exposed to communicable diseases. But groups like the National Association of People With AIDS (NAPWA) and the Lambda Legal Defense and Education Fund publicly denounced the airline. The ensuing media spotlight created a public relations nightmare for the airline. American Airlines later agreed to a legal settlement, part of which called for sensitivity training for all gate agents and flight attendants regarding the treatment of passengers with disabilities, including AIDS. Such incidents send a strong "reverse stigma" message to corporate America, declaring that such stigmatizing behavior would not be tolerated.¹

Help People Affected by Stigma Develop the Tools to Survive It—and Combat It

Stigma is unlikely to go away any time soon. PLWH/A must be empowered to cope with and overcome stigma. Multiple strategies are needed to train and support PLWH/A to advocate for themselves in a stigmatizing environment. Moreover, PLWH/A should not bear the entire responsibility for identifying and combatting stigma. Rather, community leaders, government agencies, and health care providers must form real partnerships with PLWH/A to effectively combat stigma.

Develop Legal and Regulatory Responses to Protect People From Stigma and Discrimination

Stigma often manifests itself in discrimination. By enacting legal and regulatory responses to discrimination and stigma, a more welcoming and safe environment for PLWH/A can be created.

Provide Effective HIV/AIDS Care and Treatment

The availability of effective treatment in the United States has changed the public image of PLWH/A. In the 1980s, PLWH/A were perceived as bed-ridden individuals visibly marked by Kaposi's sarcoma and other opportunistic infections. Today, the public image of PLWH/A is more often that of a vibrant, healthy person actively managing a chronic illness. Treatment advances also foster an image of PLWH/A as productive, contributing members of society, not a burden on others.

Conclusion

Since the onset of the AIDS epidemic, the HIV prevention, care, and advocacy community has implemented initiatives that counter stigma. Making stigma mitigation a part of more comprehensive HIV/AIDS-related initiatives provides an invaluable opportunity for addressing stigma in all its manifestations.

Much has been learned about the manifestations and consequences of stigma for the community, the provider, and the individual. Increasingly, the HIV/AIDS community has engaged in interventions specifically targeting stigma. Yet stigma remains a potent barrier to HIV prevention and care, and it continues to have damaging effects on the lives of PLWH/A. By developing more effective mechanisms for mitigating stigma's deleterious effects, the community of individuals and organizations concerned with HIV/AIDS can clear the pathway to HIV services for millions of individuals.

Reference

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INTERVENING WITH PROVIDERS

TO ADDRESS HIV/AIDS STIGMA

Interventions to Address HIV/AIDS Stigma Among Health Care Providers

JOSÉ TORO-ALFONSO AND NELSON VARAS-DÍAZ

Jose Toro-Alfonso, Ph.D., is an associate professor in the Department of Psychology, University of Puerto Rico. Nelson Varas-Díaz, Ph.D., is an assistant researcher at the University of Puerto Rico Center for Psychological Services and Research. In this article, they discuss the components of a replicable approach to mitigating HIV/AIDS-related stigma in health care settings.

Researchers at the University of Puerto Rico developed an intervention module to help providers reduce HIV/AIDS stigma in health care settings. The project was designed to increase providers' understanding of stigma and its consequences for people living with HIV/AIDS (PLWH/A) in Puerto Rico. Its conceptual framework draws on the work of various key stigma researchers.

Stigma is a social construct that comprises two basic parts: (1) the recognition of a difference based in a specific characteristic, "mark," or blemish, and (2) the devaluation of the person who possesses that characteristic.

In his dissertation, *Dangerous Incarnation: Stigma and HIV/AIDS*, Nelson Varas-Díaz cites the research of Erving Goffman, who defined stigma as an attribute that is profoundly discrediting and can make a person feel almost inhuman. According to Goffman, there are three principal types of stigma:

- + Abominations of the body: stigma associated with physical deformations or deviations from a social norm, such as people with physical challenges, missing limbs, or physical deformities.
- + Blemishes of individual character: stigma associated with perceptions about a person's character, identity, or simply their particular way of being. Character flaws may be attributed to people in jail, drug users, alcoholics, the mentally ill, homosexuals, and others.
- + Tribal stigmas: stigma stemming from the negative evaluation of a person due to their association with a group. Tribal stigmas may be associated with ethnicity, gender, race, nationality, or religion.

Stigma entails several dimensions, which can be summarized as follows:

- + Concealment: Can others see the stigmatized condition or "mark"?
- + Development: How advanced is the condition?
- + Disruptiveness: How disruptive is this mark to social interactions? How uncomfortable does the stigmatized condition make people feel?
- + Aesthetic qualities: To what extent is the individual visibly marked?
- + Origin: What is the origin of the condition, and who is to "blame" for its development? For example, is the mark considered the work of God as punishment for certain behaviors?
- + Peril: Is the mark associated with death and dying?

Stigma is manifested in various ways, including through social exclusion. Stigmatized people sometimes are socially excluded because they are viewed and judged according to their deviation from social norms, as defined by nonstigmatized people. They may be considered a threat to the health or security of others and may even be deemed a potential threat to national security. Social exclusion may stem from the belief that people who are stigmatized cannot contribute to society. Finally, stigmatized individuals may be excluded

because they are associated with bodily deterioration or death, which may produce negative emotions and discomfort in others.

HIV/AIDS Stigma

HIV/AIDS stigma is stigma directed toward people suspected of being infected with HIV—whether or not they are infected or exhibit symptoms. HIV/AIDS carries a high level of stigmatization for various reasons:

- + HIV is an incurable, progressive, and deadly disease.
- + Some people believe that HIV-infected individuals “get what they deserve.”
- + The symptoms of HIV/AIDS—especially in its advanced stages—can be socially disruptive.
- + HIV-infected people may be perceived as a threat to the health and security of society.

HIV/AIDS stigma is often related to other types of stigma, including those associated with sexual orientation, drug use, ethnicity, and sexual behavior. Research also suggests that HIV/AIDS stigma is often associated with misconceptions about HIV disease and its transmission. Moreover, some people believe that individuals who become HIV infected through sexual relations are to blame. In addition, HIV-positive mothers are often faulted for passing the disease on to their children.

Consequences of HIV/AIDS Stigma

There are numerous consequences of HIV/AIDS stigma. Anxiety, depression, guilt, loss of support, social isolation, difficulties with family dynamics, emotional or physical violence, and the deterioration of relations with health care providers are all results of stigmatization. PLWH/A may be abandoned or avoided. Even friends may be reluctant to visit those who are ill. Finally, stigma may drive people to deny or conceal their HIV test results.

Research reveals that people cope with stigma in a variety of ways:

- + Retiring: The stigmatized person retires, remains silent, or avoids stigmatizing situations.
- + Hiding: The person chooses not to disclose his or her HIV serostatus and refrains from commenting on the diagnosis—even to family.
- + Accepting: The individual chooses to accept and endure stigmatizing attitudes and comments.
- + Confronting: The person chooses to confront those who express stigmatizing views.

Stigma Among Health Care Providers

Research indicates the existence of stigmatizing attitudes and behaviors among medical specialists, nurses, psychologists, and other health care providers. In the health care setting, stigma often stems from a provider's lack of experience with HIV/AIDS or from a fear of contagion and death. Stigmatizing providers may avoid physical contact with a person suspected of being HIV infected, or may be less considerate of the patient's opinions about his or her treatment. HIV-infected patients may be deprived of needed physical examinations because their provider is avoiding contact. Providers may isolate or segregate patients with HIV/AIDS, disrespect their right to privacy, treat them with indifference, and fail to take into consideration the patient perspective during treatment planning.

Developing an Intervention Module to Reduce Stigma

Researchers at the University of Puerto Rico developed an intervention module to teach health care providers about HIV/AIDS stigma and, ultimately, reduce stigmatizing attitudes and behaviors. The methodology for the study involved the following steps:

Step 1: Interviews With People Living With HIV/AIDS

Interviews were conducted with 30 PLWH/A; 10 were infected through injection drug use, 10 through unprotected heterosexual sex, and 10 through homosexual sex. Inclusion criteria required that participants be Puerto Ricans who were 21 years of age or older and were receiving services at community-based organizations (CBOs). They were expected to know how they had become HIV infected and had to have experienced stigma.

All participants were recruited through three Puerto Rico-based CBOs. Fifty-three percent of participants were male, 47 percent were female, and the average age was 39. Sixty-three percent were single. Eighty percent were living in San Juan. Fifty-four percent were heterosexual, 40 percent were homosexual, and 6 percent were bisexual. More than half of the participants reported a monthly income of less than \$500. And although 63 percent were on highly active antiretroviral therapy, one-third of the participants were unaware of their viral load.

Doctoral students were trained to conduct interviews with the PLWH/A participants. Interviewers were asked to keep a diary of each interview, which provided the coordinators with insights into the interviewers' perspectives and feelings about their subjects. A qualitative analysis of the interviews—totaling about 1,000 pages—was then conducted.

Step 2: Development of the Intervention Module

Using information and insights provided through the PLWH/A interviews and assistance from experts, an intervention module was developed for pilot testing. The module was developed as a 3-hour workshop in which participants were exposed to definitions of stigma, examples in real-life health care scenarios, and strategies to cope with their own beliefs and self-stigmatizing attitudes from their clients. The module included the use of visual media (movies) and participatory exercises as techniques to provide information on AIDS stigma and skills on how to address it.

Step 3: Module Implementation and Evaluation

The module was initially implemented and pilot tested with 12 health care providers. The providers were all older than 21 and employed at an AIDS service organization. They were recruited through the Caribbean AIDS Education Training Center. Eight females and four males were recruited, with an average age of 45. The average monthly income was \$2,451. The group consisted of nurses, physicians, health educators, and a nutritionist. Seventy-five percent reported social interaction with PLWH/A on a daily basis. Instruments included a screening tool, sociodemographic questionnaire, and an in-depth interview guide, as well as an evaluation questionnaire to ensure participant feedback.

The providers' evaluations of the pilot included the following statements:

- + “Activities were helpful to address stigma.”
- + “The facilitator was well prepared and was clear in his presentation.”

- + “Facilities were adequate.”
- + “. . . kept me interested during the whole workshop.”
- + “The information received is helpful for my daily work.”
- + “The workshop met my expectations.”
- + “I will recommend the activity to other health care providers.”

More than 36 percent of the providers said they need more training on stigma, 34 percent said they needed no more training, and 27 percent did not answer the question.

Recommendations

Future projects should consider exploring the relationship between various forms of stigma, including the stigma associated with HIV/AIDS, race, gender, sexual orientation, and drug use. It is important to consider the perspective of HIV-negative people and to involve health care providers when developing HIV/AIDS interventions for mitigating stigma. The research described above found that ongoing interventions are needed to address stigma among health care providers in Puerto Rico. Stigma extends beyond the individual. It is embedded in institutions where the isolation and exclusion of PLWH/A are accepted.



Addressing Stigma in the Health Care Environment: Two Studies From Horizons

CHRISTOPHER CASTLE

Christopher Castle is program associate at the International HIV/AIDS Alliance; he directs that agency's participation in the activities of Horizons, a team of U.S. and international organizations working to prevent the spread of HIV/AIDS and mitigate its effects on individuals and communities. This article provides an overview of results from two Horizons studies.

Directed by the Population Council and funded by the United States Agency for International Development, Horizons is a team of U.S. and international organizations working to prevent new HIV infections and to mitigate the effect of HIV/AIDS on individuals and communities. This 10-year (1997–2007) collaboration provides for the design, implementation, and evaluation of innovative service delivery strategies related to all aspects of HIV prevention and care. Horizons provides capacity building in developing countries; conducts field-based operations research that identifies effective HIV/AIDS interventions and policies; tests prevention, care, support, and service delivery strategies; and disseminates and promotes the use of research findings.

Horizons' goals are to

- + identify issues affecting design and delivery of HIV/AIDS programs;
 - + test new approaches to prevention, care, and support programs; and
 - + recommend effective practices to improve policies and programs.

This article provides an overview of results from two Horizons studies. The first addressed the involvement of people living with HIV/AIDS (PLWH/A) in service delivery in four countries. The second study examined the prevalence of stigmatizing attitudes and discrimination in hospital settings in New Delhi, India, and implemented programs to mitigate them.

Study 1: Greater Involvement of PLWH/A in Service Delivery

Horizons implemented a study to evaluate how PLWH/A are involved in nongovernmental organizations (NGOs) and community-based organizations (CBOs) delivering prevention, care, and support services at the community level. Researchers wanted to identify how factors—including stigma—limit or enhance PLWH/A involvement in these organizations in four countries: Burkina Faso, Zambia, Ecuador, and India. The study reflected growing recognition of the importance of PLWH/A involvement in the delivery of prevention, care, and support services in developing countries. It also highlighted the need to ensure that Greater Involvement of People Living with HIV/AIDS (GIPA) principles are reflected in service delivery activities. Specifically, the study was designed to

- + describe current ways PLWH/A are involved in NGOs and CBOs;
 - + identify factors that limit or enhance PLWH/A involvement in these organizations;
 - + examine whether PLWH/A involvement in NGOs and CBOs can improve their quality of life as well as the quality of life for the PLWH/A community at large; and
 - + understand how PLWH/A involvement can affect the relevance, quality, and effectiveness of the services provided by NGOs and CBOs.

The study was participatory and diagnostic. It was not designed to compare interventions; rather, it used primarily qualitative measures to gain a better understanding of PLWH/A involvement in NGOs and CBOs. There were 745 respondents, including the following:

- + HIV-positive and HIV-negative staff and volunteers from 17 NGOs in the four countries
- + HIV-positive and HIV-affected service users
- + Relatives of PLWH/A involved in NGOs
- + Health care workers, policy makers, and community leaders.

Research Summary

Stigma and discrimination were identified as the “most limiting factors” for PLWH/A involvement in HIV-related service planning and delivery in each of the four countries participating in the study. This was the case regardless of HIV prevalence or levels of response to the epidemic. According to study data, stigma and discrimination were critical barriers to PLWH/A involvement in NGOs and CBOs.

Moreover, discrimination by health care workers was widely observed—by both PLWH/A and service providers—in all four countries. In Ecuador, for example, a woman who was about to give birth was told by the attending physician that because she was HIV-positive she would have to undergo a tubal ligation to prevent future pregnancies. In India, a service provider reported that employees refused to bathe HIV-infected patients.

Fear of having one’s serostatus discovered and being stigmatized was substantial for PLWH/A staff members, volunteers, and clients. This fear was widely reported in Burkina Faso in particular, where a service provider reported that many PLWH/A at one institution were afraid that CBO staff would discover their HIV status.

Mitigating Stigma: What Providers Can Do

- + Assess staff attitudes and provide sensitivity training as necessary.
 - + Review policies and procedures and modify those that discriminate or stigmatize.
 - + Ensure confidentiality for all PLWH/A, whether providers or clients.
 - + Allow PLWH/A to make their own decisions about disclosure and visibility.
-

Still, the study did find that PLWH/A involvement in NGOs did not always result in stigma and discrimination. Moreover, family, religious, and community support was found to be instrumental in encouraging PLWH/A involvement. One HIV-positive service provider in Zambia, for example, reported that the support of her child made a huge difference in her involvement. An HIV-positive client utilizing services said that having her parents accept her status made dealing with HIV much easier.

Data from the study revealed that managers often underestimated the prevalence of stigmatizing attitudes among their staff and volunteers. Moreover, many people were unaware that certain attitudes, practices,

and organizational policies were stigmatizing or discriminatory. The study found many cases in which the need for confidentiality for PLWH/A had been overlooked. Finally, the research underscored that PLWH/A should be empowered to make their own decisions regarding disclosure, and confirmed that those who were involved in CBOs may not have disclosed their serostatus beyond the walls of their organizations.

Study 2: Reducing AIDS-Related Stigma

This study examined efforts to reduce AIDS-related stigma and discrimination in hospitals in India. The Horizons Project conducted the study in conjunction with the Institute for Economic Growth and SHARAN, a New Delhi-based NGO serving the urban poor. Before the study was initiated, there had been reports of denied or delayed medical care to PLWH/A. India's National AIDS Control Organization had provided some training on HIV/AIDS management, but more work was needed to counter stigma and discrimination.

The study was implemented in the context of rapidly increasing HIV/AIDS prevalence in India. The objectives for this study were to:

- + identify causes and manifestations of stigma and discrimination of PLWH/A in clinical settings,
- + identify providers' infection control practices and challenges, and
- + develop and assess participatory interventions to create a hospital environment that was safer and friendlier to PLWH/A.

Three hospitals agreed to participate in the study. To secure their participation, coordinators borrowed from the "baby-friendly hospital concept" used in India to encourage hospitals to be more welcoming of mothers and to promote breastfeeding. Researchers found that the way they presented the study influenced the hospitals' willingness to participate. For example, clinicians who may have been reluctant to participate in a study about hospital-based stigma and discrimination were eager to participate in a study about ways to make hospitals more PLWH/A-friendly.

Of the three hospitals, two were public and one was private; all were located in New Delhi. Four departments participated in the study: general medicine; obstetrics and gynecology, skin and sexually transmitted diseases, and surgery. It was conducted in four phases over a 3-year period, beginning in 2000 and ending in 2003.

Consultation with 35 health care workers and 34 PLWH/A and their caregivers informed the formative stage of the study in 2000. At baseline, about 835 health care workers completed a survey. In addition, researchers observed staff in practice and conducted focus groups with 40 PLWH/A. Interventions to address stigma were implemented from 2001 through 2003.

Research Summary

Consistent with earlier findings, PLWH/A and their caregivers reported differential treatment in the health care setting. In addition, health care workers expressed fears about HIV/AIDS and demonstrated gaps in knowledge about the disease. Universal precautions to prevent the transmission of HIV infection were not always implemented, and researchers noted a lack of hospital-specific guidelines on HIV/AIDS care and safety.

In response to the preliminary findings, coordinators developed a PLWH/A-friendly checklist as a self-assessment tool. The checklist was designed to improve the hospital environment for PLWH/A and other patients and to improve staff safety, competence, and comfort in treating patients of known or unknown HIV status. The checklist covered access to care, counseling and testing, confidentiality, infection control, and quality of care.

Results of the study showed that 30 percent of participating doctors reported that invasive procedures on patients with HIV/AIDS had been delayed, presumably because of their serostatus. In addition, 43 percent of nurses reported segregating or isolating patients with HIV. Participants also reported a notable lack of linkages to community-based care and support services.

The two public hospitals participating in the study had voluntary counseling and testing centers, but only one had trained counselors. Only 6 percent of physicians had been referring patients for testing and counseling services. At the private hospital, HIV testing was a prerequisite for all invasive procedures but no pretest counseling was required and no patient consent procedures were in place.

Hospital Actions to Improve Environment for PLWH/A

- + Pilot curriculum and manual to sensitize health care workers.
 - + Develop institutional HIV/AIDS guidelines.
 - + Develop posters on infection control and postexposure prophylaxis.
 - + Develop directory of local services for PLWH/A.
 - + Train counselors.
-

Researchers identified many instances in which health care workers disclosed a patient's HIV status to non-treating hospital staff. The study found that 96 percent of nurses reported that they divulged patients' HIV status to other ward staff. Researchers observed that individual beds, patient files, and hospital wards often were marked to indicate the person's HIV status. For example, in some cases the letter "X" was drawn across the end of the patient's bed. In other cases, biohazard stickers were placed near beds to indicate a person's HIV status.

The study found that 77 percent of ward staff had no training in infection control procedures. Even employees who had frequent contact with blood or other bodily fluids had not received proper training regarding handling and disposal. Shortages of essential supplies, including water, were widely reported and observed, limiting the hospitals' ability to meet hygiene needs. The study also found an almost complete lack of awareness about postexposure prophylaxis and its place in hospital policy.

Basic knowledge about HIV was high by some measures, although myths and fears about transmission were observed. For example, 51 percent of ward staff believed that transmission could occur through

mosquito bites. The study also noted judgmental attitudes among health care workers, some of whom believed “PLWH/A are bad people who deserve what they get.”

Although the public-hospital managers all claimed to follow the National AIDS Control Organization policies, few staff members were aware that the policies even existed, let alone how to put them into practice.

The first step in the intervention phase of the study involved sharing baseline data with all levels of hospital staff. Those data were then compared with data from the self-assessment checklist to stimulate discussion about individual beliefs and perceptions. Action plans were developed to help the hospitals become more PLWH/A-friendly. Using published materials on infection control, prevention, and universal precautions, study coordinators developed a sensitivity-training curriculum.

Coordinators also helped develop and disseminate institutional HIV/AIDS guidelines. The policy guidelines on HIV/AIDS included infection control, access to and provision of care, counseling and testing, confidentiality, training for hospital staff, and HIV/AIDS policy dissemination. Highly visible, graphics-based posters about infection control were developed, and coordinators helped generate directories of locally available services for PLWH/A in an effort to encourage referrals and linkages.

Comparisons of data from pre- and posttraining surveys suggested that the training initiatives were having a positive effect on staff attitudes toward PLWH/A. In some cases, sensitivity scores increased but then tapered off after 2 months, reinforcing the need for a culture of ongoing training and retraining. Managers were instructed to use checklists and action plans to assess progress over time. At the end of the project, researchers plan to conduct a survey to evaluate the impact of the intervention.

Conclusion

Both studies illustrate that building trust with hospitals and care providers is essential to effective change. These Horizons activities underscore the importance of manager participation in designing projects and research and disseminating tools. The study found that giving hospitals a sense of ownership may increase the sustainability of the initiatives. Data indicate that provider attitudes and concerns typically reflect those of the wider community and therefore have a significant influence on the community as a whole. Finally, these studies emphasize the need to assess stigma and discrimination from the PLWH/A perspective.

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STRATEGIES AND CHALLENGES:

VULNERABLE POPULATIONS

Stigma in HIV and Corrections: An Interview With Elizabeth Craig

Elizabeth Craig is a noted expert on HIV in correctional settings. She is resources coordinator for the GRACE (Guiding Responsive Action in Corrections at End-of-Life) Project, which promotes high-quality hospice and palliative care for terminally ill inmates of jails and prisons across the United States.

- Q. Ms. Craig, please begin by giving us a quick lesson in terminology. How do jails differ from prisons or departments of corrections?

A. Basically, jails generally serve as short-term detention for those found guilty of minor crimes, individuals awaiting court dates, or individuals who are waiting on a transfer to prison. It is much more difficult to identify people in jails who need health care because inmates are moving in and out so quickly. The atmosphere tends to be chaotic. Prisons, or departments of corrections, are long-term facilities. It is less difficult to keep track of inmates in prisons because the environment is more stable.

Q. What kinds of stigma do HIV-infected individuals in jails and prisons face?

A. HIV/AIDS stigma among the incarcerated is compounded by other stigmas. Inmates are stigmatized because they are in jails or prisons. In addition, inmates may face the stigma of injection drug use and sexual orientation. Race is possibly the most stigmatizing. There are so many Black people in prisons. There is something completely wrong. The number of people of color in jails and prisons is highly disproportionate. And, finally, if inmates are ever fortunate enough to be released, they face the stigma associated with being an ex-con or an ex-offender. So, in addition to stigma attached to a deadly disease, incarcerated individuals have many other forms of stigma to contend with.

Q. Does HIV stigma exist among those who provide care for infected inmates?

A. Many health care providers in corrections, as well as other workers in corrections, harbor stigma against HIV-infected inmates. But this does not mean that they are uncaring individuals. In fact, these caregivers are trying to provide care to a huge, diverse population with limited resources. Often health care providers lack accurate information and they do not possess the knowledge needed to effectively treat infected inmates.

Q. Are there correctional facilities that segregate inmates who are infected with HIV from the general incarcerated population?

A. Segregation is a huge issue. In the mid-1990s, for instance, there were approximately 16 States where inmates with HIV/AIDS were segregated from the general population. The facility in Alabama is the only one that I know of now that has one prison where all HIV-infected inmates are housed. That approach is generally looked down upon by the correctional health care community. At this point, people are feeling that HIV/AIDS patients should not be segregated.

- + HIV prevalence in correctional settings is estimated to be 7 to 10 times greater than in the general population.¹
 - + The number of people incarcerated has skyrocketed since 1990, leaving correctional institutions overcrowded and underfunded.
 - + In 1997, the most recent year for which complete data are available, 528,848 people were released from State and Federal prisons and more than 7 million were released from city and county jails. As many as 38,894 releasees were living with AIDS; 157,661 more were living with HIV infection that had not yet progressed to AIDS.²

¹ Freudenberg N. Jails, prisons, and the health of urban populations: A review of the impact of the correctional system on community health. *J Urban Health*. 2001;78:214-35.

² Hammett TM, Harmon MP, Rhodes W. The burden of infectious disease among inmates of and releases from US correctional facilities, 1997. *Am J Public Health*. 2002;92:1789-94.

Q. Why?

- A. There certainly tends to be more HIV stigma attached to inmates who are segregated. The same principles that apply to HIV-infected individuals who are identified on the outside of correctional facilities also apply to incarcerated individuals. If inmates test positive and are segregated from the rest of the population they are ostracized from what little community they have available.

On the other hand, some HIV-infected inmates may prefer segregation because they believe it provides them with a safe haven, a place where they will not be subjected to HIV stigma and ridicule by other inmates. Some HIV-infected inmates may desire protective custody more than they desire social contact. In addition, some may view the segregated body as an ongoing support group. Some people in corrections justify segregation by believing that the infected inmates would be treated better by caregivers. And some believe segregation would provide HIV-infected inmates with better access to medications and specialists. The stigma attached to an inmate housed in a segregated unit is tremendous.

Q. Is HIV stigma an impediment for inmates who need to be tested?

- A. Yes. HIV stigma manifests itself in many ways for individuals in correctional facilities. An inmate who is tested for HIV may experience the same kinds of harassment as inmates who are known to be infected. Victims of HIV stigma may be subjected to many kinds of harassment. They may be isolated socially, they may be physically assaulted, or they may have items stolen or privileges taken away.

Q. Are inmates given mandatory HIV tests upon entering jails and prisons?

- A. No. Most departments of corrections [prisons] do not have mandatory testing. The National Commission on Correctional Health Care says there are many issues involved in mandatory testing. One is liability. The commission is trying to assess the liability to departments of corrections if an inmate comes in and does not test positive, and then his or her serostatus changes [during incarceration]. No jails have mandatory testing. Inmates are generally in jail for a very short period of time.

Q. How do inmates find out their HIV status?

A. Many inmates already know their HIV status upon entering the correctional facility. Others get sick during their incarceration, which leads to a diagnosis. Others self-identify—which is fraught with issues involving HIV stigma. So many inmates have the attitude, “If I don’t know, they won’t know. If I don’t seek treatment, they won’t figure it out.” For some, denial is better than dealing with the stigma that accompanies HIV diagnosis.

Q. In addition to stigma, what are some of the other challenges to delivering health care to people living with HIV/AIDS in correctional settings?

A. There are so many issues that affect health care delivery in correctional settings. First, jails are intrinsically unstable environments, with individuals going in and out all of the time. In some ways, a jail resembles a revolving door. Second, inmates may have HIV. They may have AIDS. They may have TB. They may have hepatitis C. However, they often do not know their own medical history, which hampers treatment. And third, there are the issues inmates face upon their release. They probably don’t have much money or family or other support systems, and they face a lack of continuity of care, poor linkages to community resources, and a lack of discharge planning. All of these problems have to be addressed with limited resources.

Q. What exactly is meant by “continuity of care” and “linkages,” and why are they important?

A. Continuity of care is so important. Individuals are released from jails and they often return to where they came from. For some folks that is back to their families. For others who do not have families it could mean they will be going back to homeless shelters or to the streets. Discharge planning is a key issue.

HIV-Positive State and Federal Inmates

Year	Number of State and Federal Prison Inmates	Number of HIV+ Inmates	HIV+ Prison Population (%)
1995	1,054,609	24,256	2.3
1996	1,085,500	23,881	2.2
1997	1,137,429	23,886	2.1
1998	1,167,273	25,680	2.2
1999	1,226,524	25,757	2.1

Source: Maruschak LM. *HIV in Prisons and Jails*, 1999. Washington DC: Bureau of Justice Statistics; 2001. NCJ 187456.

There is a serious lack of funding available for discharge planning. More caseworkers are needed to provide inmates with the information about where to go for health care and medication after they are released. Linking inmates with providers before they are actually released is crucial. Funding is needed to create public health models that can escort people from the inside to the outside. This would include talking with and working with the same health care provider after they get out. How are you going to get treatment? How are you going to get your medication? Not to mention the other issues, such as housing and food.

Q. How do facilities handle patients going in and out of corrections with any continuity?

A. In different ways. In New Orleans, for example, there has been a change in how medical care is delivered. The facility now has an infectious-disease physician. One of the changes he implemented was to actually keep track of medical information on the AIDS patients. Before, patients would come into the system for a couple of days, go back out, and when they came back to jail again there was no record of that patient having been there, much less the patient's specific medical history. There was a policy in place where every time a person went to jail, he or she received a new booking number. When this changed, patient medical information was much easier to handle. These seemingly small reforms are so helpful.

Q. What can correctional institutions do to help individuals better deal with HIV stigma, both while they are incarcerated and when they are released?

- A. Peer education programs are key. There are five components to effective peer education programs. First, there is intake education. Everyone entering a correctional facility should receive the same amount of HIV information. Second, pre- and posttest counseling services should be in place. Third, HIV prevention counseling services should be in place. Fourth, treatment education. The final component is prerelease counseling.

Q. Should peer education programs be mandatory in correctional facilities?

A. There should be mandatory peer education programs in each correctional facility. The programs should include counseling for all inmates as they enter the facility. Additional counseling should be provided prior to an inmate's release. In addition, programs should include pre- and posttest counseling for inmates who are tested. HIV counseling should also be available for inmates who request it at any time.

Q. What are the major challenges to peer education programs?

A. There are many challenges. Four of the most common challenges are administrative support, professional support, social stigma, and motivating peer educators. Administrative support is something that you will never be able to do without. It is not just cursory support. It actually requires someone who has a fair amount of buy-in to the program that you are trying to implement. Professional support: Are there enough people involved in this program to make it work? There is social stigma attached to being involved in HIV/AIDS peer education—I think that is fairly obvious. And motivating peer educators. In the context of stigma, motivating educators to work in an HIV/AIDS program can produce various obstacles. But it can be done.

Q. Has the situation for HIV-infected individuals in correctional facilities improved?

A. Yes. There have definitely been advancements in health care for prisoners with HIV. For example, I've been told that, in the Philadelphia jail system, all of the officers used to wear masks. They no longer do, so they have definitely come a long way. But despite our progress, there are many issues HIV-infected inmates face. Stigma is one of them. It is significant, and divulging HIV status is still something inmates must consider. And if stigma is so strong that an individual decides not to be tested or seek care, then we are right back where we started.

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RESPONDING TO STIGMA:

PERSPECTIVES OF PEOPLE LIVING WITH HIV/AIDS

Responding to Stigma: The Perspective of a Person Living With HIV

NAISIADET MASON

Born in Kenya, Naisiadet Mason is known internationally as an advocate for people living with HIV disease. Currently at the Joint United Nations Programme on HIV/AIDS (UNAIDS), Ms. Mason previously served as director of international programs at the National Association of People Living with AIDS (NAPWA) in Washington, DC.

I was born and raised in Kenya, where young women between ages 15 and 24 are twice as likely to be HIV-infected as are men in the same age group.¹ The latest UNAIDS statistics say that 55 percent of new HIV infections are among women. Sixteen years ago, while still living in Kenya, I was diagnosed with HIV. My husband was diagnosed 6 months after I was. He died 2 years later.

My story begins like many others. As the married mother of two, I was naïve about the risks for HIV. After all, I was involved in what I thought was a monogamous relationship. I foolishly believed that HIV was *only* for sex workers. I really believed I was immune. I now know that I was wrong.

Looking back, it is easy to see that I should have known that I was at risk. Many of the signs were there. My husband liked to go out with his friends. They were heavy drinkers who spent every weekend at the local bars. Many times, he would not come home until 3:00 a.m., if he came home at all. In addition to my husband's behavior, there were other signs: I had two STD infections prior to my HIV diagnosis. After the first incident, I talked to my husband about using condoms. As is common among married men in Kenya, he refused. Why would a man use a condom with his wife? I insisted that we use condoms. He beat me up.

After a while, I decided to take a different approach. I visited his parents and asked them to speak with him about using condoms. They refused. At one point, I even went to the police. I told them my husband was beating me. They responded by telling me that my husband was simply disciplining me and to go back home. Despite the fact that I was educated to Level 6—community college in Kenya—negotiating with my husband to use condoms proved impossible.

In 1990, my husband had just died. I was sick, and I had two small children to care for. I was frustrated, angry, and in denial. At the time, I was fortunate to be working for Barclays Bank. I made the conscious choice to continue working and to spend the rest of my time focusing on my children. I ignored the HIV. I got away with those choices for 4 years. Then I began to suffer opportunistic infections. I made so many large medical claims that my employer investigated and uncovered my secret. You guessed it: I lost my job.

I am not sure what would have happened if it had not been for my friends. We were able to come up with \$100. With the money, I bought a wooden shack, or kiosk, and from there, I sold milk, sugar, salt, and those kinds of things. I somehow was able to care for myself and my children for a while. But eventually, my health began to deteriorate. I recognized that I needed support from others.

Along with other women in Kenya, I founded the organization Women Fighting AIDS in Kenya (WOFAK). Initially, the organization was just a support group. Eventually, we were able to help women in situations

similar to my own. We provided HIV/AIDS education, we tried to help women get health care, and sometimes we gave them money from our own pockets. As WOFAK grew, we were able to establish paid positions. We worked all over Kenya to help women.

In 1996, I came down with pneumonia. I could not breathe, much less care for myself or the children. My daughter, who was 6 at the time, had to do all the cooking. Those who have been to the developing part of the world know that the cooking devices are very primitive. My daughter was cooking for our family with metal and charcoal. This went on for several days. Finally, a family member came to care for me. She made sure that I ate and was able to get my Catholic priest involved. I was able to see a doctor and, even though I did not have enough money for medications, I got better.

It was not too long after this that my sister, who was in school in the United States, came to visit me. It was clear to both of us that I would die very soon if something was not done. There was a lot of talk about anti-retroviral medications (ARVs) in the United States. We knew that if I was going to live, I had to have access to the medications.

We found a way to get me to the United States. At the time, my T-cell count was at 94 and my viral load was in the millions. Within 3 months of getting ARVs, my T-cell count rose to 400. With that, I got new hope for life: I began planning—not to die, but to live.

I began to get better and began to get more active. I finished my undergraduate degree, and I got my master's degree. In Minneapolis, I began working with other people who are living with HIV/AIDS. And I got involved with the Society of Women and AIDS in Africa (SOWAA).

Our main goal at SOWAA is to empower women. So many women, especially in underdeveloped countries, live in a state of extreme vulnerability. We believe that empowering women is fundamental to reducing the vulnerability of women, especially young women. Unless we are able to empower women, elevate their status, confront the issues of gender violence, and address cultural issues women will continue to be at high risk for HIV/AIDS.

Until just one year ago, SOWAA depended solely on volunteers. Now we have chapters in more than 40 countries. Some of the chapters function out of briefcases, others out of people's homes, and still others out of private offices. Our national office is in Kenya. In each of the chapters, we work to ensure that a legal system is being designed to help women address issues.

We also try to address and reduce the effects of stigma. For example, in many parts of Africa, women are not allowed to inherit property. If a woman loses her husband, his family comes in to claim what was his. This usually leaves women and children at the mercy of family and community. In some places, the woman is inherited by the husband's brother. If the woman has HIV, transmission could occur over and over again. So the SOWAA in Kenya is working with volunteer lawyers to try to educate them about inheritance issues as well as other issues that women face.

We also work with religious organizations. Our main objective is education, so that churches will have a less moralistic, judgmental approach to people living with HIV. Churches are a pillar of society and are instrumental in determining how cultures deal with HIV. If we can help churches to embrace people with HIV and

show compassion toward their loved ones, people in the general population will follow their lead. The best way to accomplish this goal is get religious leaders involved. As more and more religious leaders are becoming infected, the fact that no one is immune to HIV is becoming clearer.

SOWAA believes that the role of religious institutions is twofold. First, they can provide positive, informative messages to the community. Second, they are very well placed to provide counseling and support services within their institution. Religious institutions also could be involved in the fight against HIV by visiting and providing services within the homes of HIV-infected families.

SOWAA focuses many of its resources on young women. One of most crucial issues is education. As we all are aware, many young people simply do not know how HIV is transmitted. We feel if we can reach young girls before they become sexually active, we may be able to spare some of them the horror of HIV. There are many cultural barriers to educating this population, however. One such barrier has been coined "Sugar Daddy Syndrome." This occurs in many of the poorest countries, where so many families are struggling to keep their families fed. Many live on less than \$1 per day. In order to help out—or to survive, in many cases—young girls are selling themselves for sex for whatever they can get. The Sugar Daddy Syndrome is putting many young girls at risk.

We have seen some changes since SOWAA began to advocate for young girls. In Kenya, for example, tuition previously had to be paid for children to attend primary *and* secondary schools. In families where there was more than one child, it was a financial impossibility for every child to attend. In those cases, male children were allowed to go to school and female children were put to work. When we got a new President, he mandated *free* primary education for all children. An eighth-grade education for a young girl in Africa is much better than no education at all. I am not saying that SOWAA deserves all of the credit for this change, but I do believe that our organization, as well as others like it, is making an impact.

Young women in Kenya hold critical positions within the society. First, women are most often the main caretakers of the family. Women take care of aging members of the extended family as well as young children, while providing all the daily needs of the entire family. Second, women can transmit HIV to their children: Babies are delivered naturally and are breastfed. It is critical that women who are of childbearing age be educated about maternal transmission of HIV. Third, statistics tell us that in Kenya women are more likely than men to become infected. However, it is incredibly difficult for women to practice safe sex. Finally, women contribute greatly to certain economic sectors in Kenya. They provide cheap labor in the fields, and they are most of the teachers and fill many of the positions in the service industry. For all of these reasons and for many more, I advocate on behalf of the women fighting AIDS in Kenya and around the world.

Reference

¹ U.S. Agency for International Development (USAID). *Leading the Way: USAID Responds to HIV/AIDS, 1997–2000*. Washington, DC: USAID; 2001. Available at: www.dec.org/pdf_docs/PNACM861.pdf.

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Responding to Stigma: The Perspective of a Person Living With HIV

JOSE WILLIAM MELENDEZ

Jose William Melendez is community mobilization and technical assistance field manager at the National Latina/o Lesbian, Gay, Bisexual, Transgender Organization (LLEGO). In this article, he reflects on the impact of HIV/AIDS stigma in his own life and on the challenges the HIV services community faces to provide a more proactive response to stigma and its fundamental causes.

I work for LLEGO, the only national nonprofit organization devoted to representing Latina and Latino lesbian, gay, bisexual, and transgender (LGBT) communities. We address issues ranging from civil rights and social justice to health care and social services. We develop interventions to address the social, health, and political disparities that stem from discrimination based on race and ethnicity, sexual orientation, and gender identity. Throughout our 16-year history, LLEGO has created innovative programs for educating and mobilizing Latino/a LGBT leaders and organizations on local, national, and international levels.

My job at LLEGO is to provide a means for people to acquire and develop the skills they need to address stigma. LLEGO has developed a workshop on disclosure—both for HIV-positive and HIV-negative people. The workshop was presented at the Ryan White Youth Conference in 2002. Sixty-four individuals participated—men, women, youth, and older people. Many had never had the opportunity to talk to each other, to sit across the room from one another and say, “These are my fears as an HIV-negative person” or “These are my fears as an HIV-positive person.” The workshop experience was very powerful for these individuals because stigma must be acknowledged before it can be addressed. Acknowledgment alone will not resolve the problem, but it provides a starting point.

Neither I nor most people my age have ever known a world without AIDS. Yet we have benefited from the efforts of the LGBT generation before us; those who fought for our rights and imparted essential knowledge about HIV disease and its prevention. So it is not surprising that when someone from my generation becomes HIV-positive, the reaction often is, "You should have known better. You inherited all these rights. You have all this education. How could you become infected?" I think that this says much about communication between generations and about people who are HIV-negative and those who are HIV-positive.

A starting point for LLEGO was the creation of a Latino young gay and bisexual men's leadership development program. We realized immediately that we could not ignore Latina lesbians and Latino transgender individuals. They needed to be included because "stigma is not created in a vacuum of gay and bisexual men." Lesbians and transgendered people are affected as much as we are. We gathered the council at the beginning of the program and we talked about the issues facing Latina and Latino LGBTs. It was a powerful experience for everyone involved. They were able to come to the table and realize that there is no shame in their identity as young, Latino, and queer. Stigma and homophobia are a part of a continuum of oppression. Thus, any efforts to separate their effects or to try to differentiate the various parts of one's identity are problematic and emblematic of the discrimination one faces.

In Spanish *estigma* and *pena* mean shame; they are so intertwined that there is a fundamental inability to speak about either one. Stigma is related to our inability to talk about fundamental underlying issues, from safer sex to women's rights, from racism to socioeconomic disparities. Stigma often shames people back into the closet, discouraging them from accessing needed health services. Moreover, stigma can cause people to hide or deny their HIV status, sexual orientation, or histories of rape or child abuse. For me, disclosure is about coming out as an HIV-positive young Latino gay man. However, disclosure is also important for HIV-negative people, because of the power associated with a negative status. We cannot speak about one identity politic without the opposite. We must be able to formulate an HIV-negative identity without creating a shameful discourse about an HIV-positive identity.

At LLEGO we talk about the complexities of stigma. Stigma as defined by culture and communities in relation to the practice of discrimination. The roots of stigma are related to cultural norms that foster community, *familia*, and collective thinking. The discrimination experience occurs when this communal experience is replaced by individualistic, personal ways of thinking and acting—usually a result of breaking the silence established by norms. When someone becomes HIV-positive and that person is, for example, a Latina woman, the stigma she faces is compounded. She may have been facing an incredible burden of stigma long before she became HIV-positive, and the stigma was solidified once she seroconverted.

As health care providers, I think of our responsibility and accountability to those who have access to policy makers. If we do not deliver messages to policy makers, then we are perpetuating the silence. We need to acknowledge that maybe we are not doing enough to fight stigma. We cannot oversimplify messages, yet we cannot allow ourselves to become stuck on identity politics.

We need to learn from Audrey Lorde's perspective on what she calls the "ladder of oppression" or intersection of experiences. As a Black lesbian survivor of rape, Lorde tries to decide whether her identity is primarily that of a lesbian, a Black lesbian, or a Black lesbian survivor of rape. She goes back and forth, finally realizing that she cannot make a choice. She is one and all; the experiences of oppression as a result of her different identities create histories that are not to be compared or denied. Similarly, in the Latino community, the Latino gay community, or in the Latino immigrant community, our identities form a matrix. We cannot choose one component of ourselves over another. We cannot choose one form of stigma or discrimination over another. We cannot make those choices, because to do so would perpetuate the shame, the *pena*—the stigma.

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SELECTED INTERVENTIONS

FOR ADDRESSING HIV/AIDS STIGMA

Mitigating the Effects of HIV/AIDS Stigma: The POLICY Project Responds

KEVIN OSBORNE

Previously associated with the FUTURES Group POLICY Project, Kevin Osborne is currently senior HIV/AIDS advisor at the International Planned Parenthood Federation in London. In this article, he discusses stigma indicators, POLICY Project activities related to mitigating HIV/AIDS stigma, and lessons learned from those activities.

Funded by the U.S. Agency for International Development (USAID), the POLICY Project is designed to work with host-country governments and civil society groups to achieve a more supportive policy environment for family planning and reproductive health, HIV/AIDS, and maternal health. The project has several goals:

- + Broaden and strengthen political and public support for family planning and reproductive health, HIV/AIDS, and safe motherhood policies and programs.
 - + Improve the operational environment for those programs, including better planning and financing.
 - + Ensure that accurate, up-to-date information informs policy decisions.
 - + Build in-country and regional capacity for policy development.

Stigma and the POLICY Project

Through their work on national HIV/AIDS policies, POLICY Project staff have recognized the various forms of stigma that plague good operational programs. Among them is the concept of internal stigma, a learned phenomenon occurring among people living with HIV/AIDS (PLWH/A) and illustrated by a comment made by a participant at the Trinidad conference of the Global Network of People Living with HIV/AIDS: "For far too long as a recognized PLWH/A leader I only wanted to blame stigma on the outside world, little realizing that I am a co-factor in its continuation."

The personal perspectives of PLWH/A and issues that indirectly and directly affect their decisions and life choices must be understood to address internal stigma. Otherwise, stigma will always remain an outside influence, rather than something that can be contained and controlled from within.

PLWHA confront the deeply entrenched effects of stigma every day. A leading HIV-positive advocate in Cambodia shares this experience: "Soon after my husband found out that he was infected with HIV, I found out that I was HIV-positive. I told my relatives. They came and took my oldest daughter away. A few months later my husband's condition became worse. He ordered me to call my relatives to see his daughter before he died, but they ignored this plea, and my husband died on April 21, 2002."

USAID Stigma Indicators

At the time of this presentation, the POLICY Project co-chairs the USAID stigma and discrimination working group, which has developed four indicators for assessing how stigma is being addressed among health care providers. The indicators do not—and are not intended to—represent a comprehensive approach to measuring HIV/AIDS-related stigma, but they provide at least a partial framework for defining the extent of the problem:

- + The number of procedures, programs, or institutions with policies and guidelines that protect against discrimination
 - + The number and percentage of health care facilities with policies and guidelines that protect against discrimination
 - + The percentage of health care providers with accepting attitudes about PLWH/A
 - + The percentage of people infected with or affected by HIV/AIDS who report experiences of fear of stigma and discrimination.

Selected Stigma-Related Activities

Project initiatives provide guidance and assistance to organizations that are developing and implementing HIV/AIDS policies and programs. Four current examples of specific POLICY Project work in relation to stigma illustrate:

Securing the Meaningful Participation of PLWH/A

It is important that PLWH/A be involved in the planning, design, and implementation of all HIV/AIDS-related policies and programs. Thus, the Project promotes adherence to the Greater Involvement of People Living with HIV/AIDS (GIPA) principles. Currently, a study is being conducted in South Africa, Belize, Cambodia, Ukraine, and Brazil to evaluate whether GIPA objectives are being met in in-country activities. Through the five-country study, researchers seek answers to questions such as, Are PLWH/A actively and effectively participating in the development of national AIDS plans? Are GIPA principles reflected in activities funded by USAID?

Creating a PLWH/A Leadership Manual

In South Africa, the Project created a PLWH/A leadership manual that addresses such specific topics as skill building, human rights, discrimination, and stigma. PLWH/A were instrumental in the design, writing, co-facilitation, and presentation of the manual. In all, 40 PLWH/A representing diverse South African organizations participated in a process that proved critical to creating a useful, relevant document. The product was 18 months in the making and could certainly have been produced more rapidly by a consultant. But taking the time to secure the effective participation of PLWH/A resulted in a more effective manual than would otherwise have been possible. The manual was released by the Ministry of Health in June 2004.

During the first workshop, conducted at the beginning of the document creation process, HIV-negative people were asked to leave the room. PLWH/A were then asked what role they wanted the HIV-negative people to play in the process of developing the manual. Were they to be full participants or just observers? Simply asking those questions helped convey to the PLWH/A that the process of constructing the manual

was theirs. It was meant not to be exclusionary but to empower PLWH/A and to recognize their role in a world where stigma and discrimination all too frequently can erode a person's sense of self-worth and empowerment.

Working With Faith-Based Organizations

Because they are linked to the success of so many other activities, reducing stigma and discrimination and promoting human rights are priorities for the POLICY Project. POLICY views human rights not just as one important aspect of HIV/AIDS policies and programs, but as the very foundation on which effective strategies to address the epidemic must be built.

Our activities in this arena are designed to improve understanding of the human rights issues related to HIV/AIDS and to provide strategies to address those issues. Given the respect and trust that they engender within communities, faith-based organizations are perfectly positioned to confront the stigma and silence surrounding HIV/AIDS. POLICY already works with a number of faith-based organizations to address stigma and discrimination, and that is an area the project will continue to expand. For example, as one component of our Stigma and Discrimination Initiative in South Africa, the project is working with faith-based organizations to test and document approaches for addressing stigma that can be replicated by other organizations.

There is the potential to expand on work surrounding the development of guidelines and policies to address care and support issues. For example, POLICY is currently working with the Anglican Church of the Church Province of Southern Africa on the development of wellness management guidelines and training. POLICY also has experience in researching issues (e.g., child survival in Nigeria, access to treatment), in developing and analyzing policy (e.g., development of national home-based care guidelines in Kenya, analysis of policy gaps regarding orphans and vulnerable children in Africa), and in supporting new approaches (e.g., grants to hospices in South Africa to adopt the “Integrated Community-Based Home Care” guidelines) that lay the foundation for the project to adapt and expand its work in care and support to involve faith-based groups.

One of the major components of this work is to promote an enabling policy environment that encourages the development of high-quality, sustainable HIV/AIDS policies and programs. POLICY has already been successful at developing participatory planning processes (e.g., the Anglican Church), drafting policies and guidelines (e.g., the Nigerian Catholic Secretariat), and strengthening networks (e.g., IRAC in Kenya, IRCU in Uganda) that provide the frameworks and institutional support systems to facilitate HIV/AIDS activities for a range of member organizations, from regional or national groups to those in local communities.

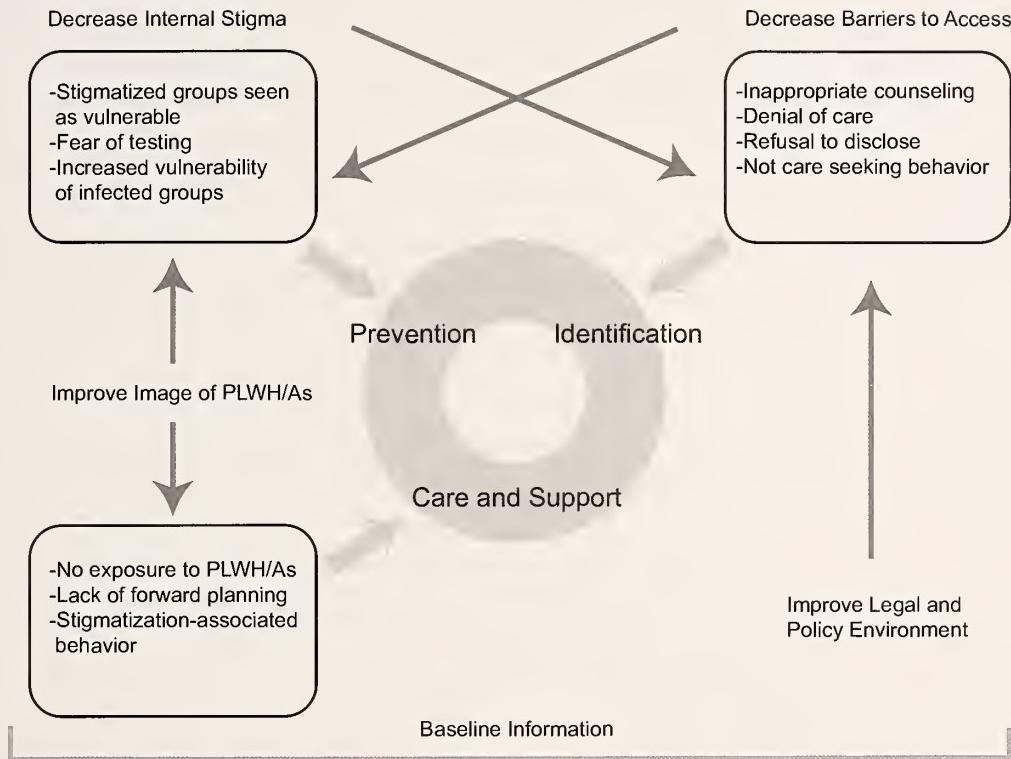
The policies and the efforts of policy champions create an environment that is itself supportive of greater faith-based involvement in HIV/AIDS activities; this is an area in which POLICY could rapidly expand its work. In addition, lessons learned from POLICY's experiences in this realm can provide models and processes that can be adapted by other organizations.

Creating New Stigma Indicators

Twin Project activities in Mexico and South Africa will generate new indicators of stigma and discrimination that will expand on the USAID indicators listed above. Partners in the initiative include the U.S. National Institutes of Health in Mexico and the Center for the Study of AIDS at the University of Pretoria in South Africa. Both locations developed indicators and tested interventions simultaneously, making the process more complex and, thus, lengthier than it otherwise would have been. The framework, reflected in Figure



Figure 1



1, borrows from that of the Horizons Project, a 5-year (1997–2002) global operations research program to prevent the spread of HIV and other sexually transmitted infections.

In Mexico, indicator development focuses on how stigma affects HIV-positive men who have sex with men (MSM) and will attempt to determine what stigma is attributable to HIV status and what arises because of sexual orientation. One component of the Mexico project examines media representations of PLWH/A. Historically, emphasis has been given to training journalists to paint a fair picture of the epidemic and those affected by it. The POLICY Project is providing training to PLWH/A on how to better interact with journalists. Acquiring the most fundamental skills, such as the appropriate and ethical use of quotes and sourcing, can make a substantial difference in how PLWH/A are perceived. The PLWH/A Photo Journal was launched at the 2004 World AIDS Conference in Bangkok.

Another project activity in Mexico is development of indicators that measure attitudes among health care providers. The project will create a journal chronicling the experiences of PLWH/A as they relate to stigma. However, the reluctance of MSM to come forward to tell their stories has been much more significant than expected. When a participating organization placed an advertisement in a national newspaper asking MSM

living with HIV to contribute to the journal, it received only three responses. This speaks volumes about fear and isolation among MSM living with HIV disease in Mexico.

In South Africa, the *Siyam'kela* (an African word meaning “we are accepting”) component of the study focuses on the nuances of a generalized epidemic. South Africa has some of the best HIV stigma- and discrimination-related policies in the world. However, policies alone do not mitigate stigma. The efforts of the Joint United Nations Programme on HIV/AIDS to apply GIPA principles in South Africa have led to the placement of many PLWH/A in government positions. It was determined that, despite workplace policies to the contrary, those individuals are experiencing alarming levels of stigma and discrimination. As a result, the POLICY Project is implementing a qualitative study within 10 South African government departments to examine stigmatizing behaviors that occur in these environments. The research is assessing stigma at every job level, in both its most overt and most subtle forms. More information and copies of relevant materials and reports on the *Siyam'kela* Project in South Africa are available online from www.policyproject.com.

Conclusion

Although many of the lessons learned from the POLICY Project are not new, they cannot be overemphasized. However, the lesson lies in operationalizing what these lessons mean in all our collective HIV/AIDS activities, as follows:

- + Empower PLWH/A: PLWH/A need to have a sense of meaningful involvement and ownership in stigma mitigation activities. Organizations should view PLWH/A as not just recipients of services but as equal partners in the development of activities. PLWA are “experts,” so redefining the definition of an HIV/AIDS expert to include PLWH/A is key.
 - + Address stigma throughout the care continuum: Although prevention and care systems historically have been considered two distinct entities, stigma should be addressed across the entire HIV/AIDS service continuum.
 - + Strengthen partnerships with PLWH/A groups and organizations: Global linkages among agencies that work with PLWH/A should be strengthened. This would mean linking more proactively with the regional and in-country offices of the Global Network of People Living with HIV/AIDS and the International Community of Positive Women.
 - + Address internal stigma: The concept of internal stigma merits greater attention. For example, many PLWH/A have had negative experiences with the health care system that directly affect sustained health-seeking behaviors and patterns. Greater attention needs to be paid to this component and finding ways to address it.
 - + Act on the GIPA principle that PLWH/A should be involved in every aspect of program planning and delivery. This is part of most international declarations and core values, but its importance lies in acting on those values in a real and practical way. There is still resistance to the concept, but organizations that have successfully implemented it have reaped enormous benefit.
 - + Set an example: Work place policies must be in place to protect, guide, and assist PLWH/A. And organizations should have a “pro-PLWH/A policy” in place to indicate that they are supportive of PLWHA in the work place. Such a policy should be part of all recruitment standards.

Reducing stigma is essential to limiting people's sense of alienation. "How do you continue to feel part of a community when people mutter behind their hands because you walk past?" was the question asked by one woman as she walked away from POLICY Project staff. The challenge of mitigating the effects of stigma in the lives of people like her requires a comprehensive approach to the problem: Stigma must be addressed across the entire continuum of HIV services, from prevention to care. No matter what policy, program, or initiative is implemented, the key question must be, "How will that activity reduce the prevailing climate of stigma?" Without answering this fundamental and yet simple question in *all* of our work, we will not reach the lofty goals of many programs.



Helping Faith-Based Organizations Respond to HIV/AIDS: The CORE Initiative

PATTY MECHAEL

Patty Mechael is project manager for the Communities Responding to HIV/AIDS Epidemic (CORE) Initiative in Washington, DC. In this article, she reports on the initiative's efforts to help community- and faith-based organizations respond to the HIV/AIDS epidemic.

The CORE Initiative is a 5-year, global program funded by the United States Agency for International Development. The mission of the CORE Initiative is to support an inspired, effective, and inclusive response to the causes and consequences of HIV/AIDS by strengthening the capacity of community- and faith-based organizations worldwide. The main approach is to leverage existing efforts while catalyzing and encouraging new efforts through diverse and innovative partnerships in the areas of community-based prevention, stigma reduction, and care and support to people living with HIV/AIDS and their families.

Leading this initiative is CARE International in partnership with the World Council of Churches, the International Center for Research on Women, the International HIV/AIDS Alliance, and the Johns Hopkins Bloomberg School of Public Health Center for Communication Programs. The partnership has maintained a presence in more than 90 countries and partners with community-based organizations engaged in a wide range of HIV/AIDS activities, including religious affiliates representing the Buddhist, Christian, Hindu, Muslim, and traditional faiths.

Faith-Based Organizations and HIV/AIDS in Developing Countries

Faith-based communities play an important role in addressing HIV/AIDS-related stigma in developing countries.

In the late 1980s, individual faith-based communities started responding to the HIV/AIDS epidemic. Buddhist monks in Thailand began calling their communities to action. In Uganda, the Islamic Medical Association developed policies on how mosques could address HIV/AIDS. The World Council of Churches began applying its experience in Europe to assist faith-based communities in Africa and Asia; and Catholic programs, such as Caritas, became heavily engaged in HIV/AIDS care and support. One American organization, Balm in Gilead, has helped increase the involvement of U.S.-based churches in addressing HIV/AIDS, both domestically and globally.

Today, faith-based organizations provide significant health care and support in resource-poor countries. A growing number of U.S.-based congregations are partnering with churches in developing countries; in some cases sending American members overseas to learn about effective programs, explore local realities and needs, and identify partnership opportunities.

Those concerned with HIV/AIDS must address the question of how to work with faith-based organizations to respond to the many challenges of the epidemic, including stigma. In 2000, a survey in Kenya helped to

highlight key issues related to the response of communities of faith to the epidemic. Survey results revealed that community members wanted to see faith-based organizations more engaged in addressing HIV/AIDS. However, the religious leaders generally responded with, “It is not our problem,” revealing a significant disconnect between community members’ expectations and what churches were willing to provide.

In 2000, U.S. President Bill Clinton hosted the World AIDS Day Summit at the White House to which he invited key religious leaders from around the world to talk about their roles in addressing HIV/AIDS. That event was the impetus for the CORE Initiative. The next year, the United Nations General Assembly Special Session on HIV/AIDS issued its Declaration of Commitment on HIV/AIDS, which called for faith-based organizations to become more involved in responding to the pandemic. The declaration made suggestions for enhancing the effectiveness of faith-based responses to HIV/AIDS, including greater participation in education and prevention campaigns, especially those aimed at addressing stigma and discrimination.

Barriers to Creating a Supportive Environment for People Living With HIV/AIDS

Unfortunately, significant barriers remain in creating a supportive environment for people living with HIV/AIDS within communities of faith:

- + Timidity regarding sexual behavior: Faith-based organizations do not like to talk about sex.
- + Controversy regarding availability and use of condoms.
- + HIV/AIDS-related stigma: The belief that HIV is the direct result of sin is widespread within religious communities.
- + Discriminatory attitudes towards women and youth: Within religious communities, gender discrimination remains common, and communities of faith may be reluctant to integrate a gender component into their HIV/AIDS program
- + Silence on advocacy and policy issues: Religious communities tend to remain silent with respect to HIV/AIDS advocacy and policy making.
- + Limited resources allocated to HIV/AIDS.

Religious communities in developing countries often are affiliated with religious communities in the United States and other developed countries. If HIV/AIDS is not a priority in the developed world, developing nations are even less likely to have the domestic resources they need to address the epidemic.

Highlights

Highlights of the CORE Initiative pilot project implemented by the Futures Group POLICY Project are summarized below:

- + Meetings of the All Africa Conference of Churches (Uganda and Senegal) provided an opportunity for religious leaders to talk for the first time with people living with HIV/AIDS. The meetings were instrumental in changing religious leaders’ attitudes and establishing productive working relationships.
- + Many members of the Anglican Church of the Province of Southern Africa are devoted to playing a positive role in the fight against HIV/AIDS. One pastor, for example, has used his understanding of theology, church dynamics, and HIV/AIDS to bridge the gap between people living with HIV/AIDS and the religious community.

- + The Islamic Medical Association of Uganda hosted a Muslim Leaders' Consultation. A second consultation was held in Malaysia. Those events spearheaded a movement within the Muslim community, and the initiative is currently exploring partnerships with Islamic Relief and other Muslim organizations.
- + Gender, faith, and HIV/AIDS: The role of female theologians and religious leaders from around the world is important when rallying faith-based organizations to the fight against HIV/AIDS. Many of those women have gathered to discuss policies of churches, mosques, and religious institutions, and they have raised awareness regarding the need to empower women as decision makers in faith communities.
- + The Small Empowerment Grants Program, a CORE Initiative pilot project, provided 45 grants of up to \$5,000 in 29 countries across three focus areas:
 - Advocacy; awareness raising; and information, education, and communications (IEC): \$131,211
 - Stigma and discrimination: \$21,400
 - Care and support: \$51,892.

Stigma Grants

A portion of resources from the Small Empowerment Grants Program was specifically allocated to address stigma and discrimination. Grant recipients included the following groups:

- + Tean Thor Association (Acts of Compassion)—Cambodia. A nonreligious nongovernmental organization, Tean Thor worked in collaboration with Buddhist monks and the Catholic Office for Emergency Relief and Refugees to reduce stigma and discrimination against children orphaned or otherwise affected by HIV/AIDS.
- + Solidarité et Echanges Nord-Sud (SENSONG) in Benin protects the rights and livelihoods of HIV-positive workers. Money from the grant helped to provide legal assistance to people living with HIV/AIDS who have lost their jobs or experienced discrimination in the work place.
- + The Livingstonia Synod AIDS Control Program of Malawi was established to help eliminate stigma so that people dying from HIV/AIDS-related causes are able to die with dignity and respect.
- + Promotion of Traditional Medicine Association (PROMETRA) in South Africa organized activities to engage the organization's 25,000-plus members in skill building, health and prevention education, and the use of nonjudgmental language to reduce stigma.

Conclusion

Involving people living with HIV/AIDS in faith-based initiatives is crucial. Their participation in meetings and conferences, for example, can help humanize HIV/AIDS for participating religious leaders. However, their involvement must be meaningful. It is important to guard against tokenism or the “poster child syndrome.”

The CORE Initiative has witnessed increased involvement of partners from the Northern Hemisphere, including mission boards, nongovernmental organizations, and religious affiliates. As a result of the President’s Emergency Plan for AIDS Relief, many U.S. faith-based organizations that had not been involved in domestic HIV/AIDS issues are increasingly working in developing countries.

Individuals and organizations working to prevent HIV/AIDS stigma and discrimination must consider how government support is solicited. With HIV/AIDS-related policy being developed at an incredible rate, organizations should be made aware of interventions and approaches that have been tested and proven effective. The AIDS epidemic has provided more than 20 years’ worth of lessons. Those lessons should inform policy making and service delivery.



The impact of faith-based initiatives that address stigma has not been well documented. It is important to evaluate results from the many studies being conducted so that faith-based organizations can continue to be a positive factor in the fight against HIV/AIDS.

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National Minority AIDS Council Curriculum for Stigma Mitigation: An Overview

RONALD JOHNSON AND FEDERICO GUTIERREZ

Ronald Johnson is public affairs education manager and Federico Gutierrez is senior public policy associate at the National Minority AIDS Council (NMAC). This article discusses training efforts to combat stigma within organizations serving minorities by developing a curriculum that focuses on the unique impact of HIV/AIDS-associated stigma in communities of color.

With funding from the Health Resources and Services Administration (HRSA), NMAC has developed a stigma mitigation curriculum and is currently providing training to minority community-based organizations serving women of color and gay men of color.

The 2-day curriculum is designed to help organizations develop interventions and strategies for mitigating HIV/AIDS-related stigma among people of color. It covers issues related to AIDS and its associated stigmas, particularly those experienced by minorities, such as racism and racial discrimination. The curriculum explores issues of self-identity among individuals belonging to many stigmatized groups—for example, men who are gay *and* HIV-positive *and* minority. Finally, it illustrates real-world, practical steps for addressing stigma inside service provider organizations.

Curriculum Development

Curriculum development began with a review of the limited literature on stigma among people of color. The curriculum draws heavily on the work of Gregory Herek and his definition of HIV/AIDS stigma: “the prejudice, discrimination, discounting and discrediting directed towards people who seem to have HIV or AIDS, and individuals or groups, or communities with which they are associated.”

The literature review also covered Herek’s analysis of stigmatized groups, including injection drug users, gay men, and minorities. Background research also included the work of Steven Thomas and Sandra Quinn regarding the belief among some African Americans that AIDS is a form of genocide and is rooted in racism, discrimination, and inequality. In addition, the research of Robert Fullilove and Mindy Thompson Fullilove provided insights into perceptions within minority communities that the victim is to blame for having HIV/AIDS.

Much consideration was given to the interplay between different kinds of stigma, because stigma associated with HIV/AIDS frequently is expressed in conjunction with one or more other forms of stigma, including those associated with sexual orientation, race, and injection drug use.

The curriculum authors examined the challenges faced by gay men of color, particularly African American and Latino gay men, for whom the central obstacle to success in HIV education and entry into care can be homophobia. Men of color living with HIV/AIDS face a triple stigma that places them at high risk for denial, isolation, emotional distress, and self-destructive behavior. The curriculum authors also paid special attention to women of color, for whom stigma remains a significant barrier to HIV/AIDS-related services.

One qualitative study, for example, found that denial and secrecy are common among minority women with HIV/AIDS, who often ignore their health care needs for fear that disclosure of their HIV status will leave them vulnerable to stigma and rejection.

Curriculum Components

The goal of the curriculum is to help providers address what they, as practitioners, can do to reduce or eradicate stigma and its effect on people living with HIV/AIDS (PLWHA), particularly women of color and gay men of color. The curriculum was also designed to help trainees identify how stigma is embedded in culture, perpetuated in society, and manifested in communities. The scope of the curriculum transcends mere education to focus on the need for stigma mitigation strategies and interventions. The curriculum addresses the impact of stigma on HIV-testing behavior; disclosure of positive serostatus; and, for the HIV-positive individual, the decision to enter care.

The curriculum is composed of six modules:

- + Module 1 is an examination of precursors to stigma and key terms associated with stigma, such as *stereotype, discrimination, sexism, racism, and homophobia*. One exercise divides participants into six small work groups, each of which is assigned a marginalized community, such as commercial sex workers, injection drug users, or recent immigrants. The work groups are asked to spend 30 to 45 minutes discussing potential challenges people in their assigned category may face with respect to stereotyping, discrimination, homophobia, and other issues associated with stigma.
 - + Module 2 is a review of disparities in HIV care access experienced by women of color and gay men of color.
 - + Module 3 is an overview of key research about the origin and prevalence of HIV/AIDS-related stigma and a discussion about stigma and discrimination in employment, health care, corrections, and housing.
 - + Module 4 presents an analysis of leading theories and concepts about stigma, including Herek's comparison of instrumental and symbolic stigma, as well as a discussion of the impact of stigma on PLWHA testing, disclosure, and access to care.
 - + Module 5 offers a discussion of the interplay between HIV/AIDS-related stigma and other forms of stigma, including those associated with race, poverty, drug abuse, imprisonment, and immigration status.
 - + Module 6 introduces multilevel intervention strategies for countering the effects of HIV/AIDS stigma at an organizational level. Participants are asked to consider ways in which they, their programs, and their organizations may be perpetuating stigma against people of color. For example, does an organization's name, setting, or marketing campaign contribute to stigma and discrimination in any way? Are staff members trained to be sensitive to and affirming of the needs of women of color and gay men of color? Are those populations really "hard to reach," or has the organization inadvertently erected barriers to access and participation by minority PLWHA?

The curriculum requires significant individual and group participation. For example, in the curriculum's last exercise, participants form small groups to design either a community- or individual-level intervention. Each group reaches consensus on which stigmatized persons their intervention will address and on what intervention or strategy they are going to employ. The interventions are then assessed and discussed after the trainees reassemble into a single large group.

Individuals who participate in the stigma training often are most interested in Modules 5 and 6, which focus on applying stigma mitigation interventions in the real world. The curriculum presents multilevel interventions that function at both the community and individual level and that target both PLWHA and those who perpetrate HIV/AIDS-related stigma.

The curriculum discusses behavioral change models, including that of R. H. Fazio, who suggests that attitudes and behaviors are formed through two processes. The *automatic process* is more ingrained or subconscious and is therefore more difficult to counter. The second process is related to cost–benefit, with changes in attitude more likely to occur when there is a perceived benefit. To effect behavioral change, the individual must consider how his or her “automatic” attitudes are expressed through behaviors and actions that may have negative consequences on both the individual and societal level. For example, by acting on negative attitudes, has the individual contradicted his or her purported beliefs about fairness and justice?

Conclusion

The HIV prevention and care challenges faced by people of color are made much more profound by the existence of HIV/AIDS stigma and by the many stigmas associated with it. The small but growing body of literature and experience regarding HIV/AIDS stigma among minorities reveal opportunities for addressing those issues. They are opportunities that must be grasped.

To date, NMAC has provided eight 2-day training courses using the curriculum described above. Individuals from all levels of organizations serving people of color have participated, including executive directors, program directors, and managers. After the training, enrollees indicate a much more profound awareness of how even well-meaning, caring organizations stigmatize the very individuals they seek to serve. This realization in itself reveals that stigma training can be instrumental in improving the HIV prevention and care environment for people of color. Bringing this awareness to providers of prevention and care services in greater numbers offers hope for mitigating stigma—and the still-growing epidemic among minorities in the United States.

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STIGMA AND HIV/AIDS

A REVIEW OF THE LITERATURE

Stigma and HIV/AIDS: A Review of the Literature

DEBORAH BRIMLOW, JENNIFER COOK, AND RICHARD SEATON

The following literature review is reprinted from Stigma and HIV/AIDS: A Review of the Literature (Rockville, MD: Health Resources and Services Administration HIV/AIDS Bureau, 2003).

This literature review was written at the request of the Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB). Its purpose is to provide technical support for attendees at the community consultation Promoting PWA Leadership in Addressing HIV/AIDS Stigma and to provide a technical assistance tool to policy makers, HIV/AIDS service organizations, and researchers concerned with the delivery of services to people at risk for or living with HIV disease.

To conduct the review, a team of three individuals carried out three independent searches. The first two searches were conducted via the Internet. The third search was conducted through the Parklawn library. Because of time limitations and the desire to keep the literature review as concise as possible, we limited our search to stigma as it specifically relates to HIV disease. Moreover, we concentrated on literature produced during the past 15 years. In all, we reviewed more than 300 abstracts and 50 publications, 47 of which are discussed in this paper.

The quantity of literature available on HIV/AIDS-related stigma differs substantially by topic area. For example, a significant number of articles are available on the evolution of HIV/AIDS stigma and on policy-related and legal initiatives for addressing it. However, we found that much less material is available on programmatic solutions. This finding is disheartening given providers' need for examples of practical, real-world interventions to decrease HIV/AIDS-related stigma.

The participation of a few key leaders often propels research in many HIV/AIDS-related fields. The study of HIV/AIDS-related stigma is no exception. Gregory M. Herek is generally recognized as a leader in the field, and his works are referenced in many of the articles we discuss.

The existence of HIV/AIDS-related stigma has been widely documented. In a comparison of two studies conducted among similar samples, the proportion of the U.S. population that harbored HIV/AIDS-related stigma increased from 20.5 percent in 1991 to about 28.8 percent in 1997. However, a more recent Centers for Disease Control and Prevention (CDC) study found a somewhat lower percentage of people who harbor HIV/AIDS-related stigma (18.1 percent).

Stigma related to HIV/AIDS appears to be more severe than that associated with other life-threatening conditions. It also extends beyond the disease itself to providers and even to volunteers involved with the care of people living with HIV disease. Often, HIV/AIDS-related stigma is expressed in conjunction with one or more other stigmas, particularly those associated with homosexuality, bisexuality, and injection drug use. People with certain religious beliefs and less educated people may be more likely to harbor HIV/AIDS-related stigma.



Summary

HIV/AIDS-related stigma compromises the well-being of people living with the disease. Stigmatized individuals may suffer discrimination that can lead to loss of employment and housing, estrangement from family and society, and even increased risk of violence. HIV/AIDS-related stigma also fuels new HIV infections because it can deter people from getting tested for the disease, make them less likely to acknowledge their risk of infection, and discourage those who are HIV-positive from discussing their HIV status with their sexual and needle-sharing partners.

Efforts to address HIV/AIDS-related stigma have focused on three arenas: programmatic, legal, and policy. The literature on effective interventions is skewed to the legal arena; a comparatively small amount of material is available on community-based interventions.

Stigma Defined

HIV-related stigma refers to all unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as toward their significant others and loved ones, close associates, social groups, and communities. Patterns of prejudice, which include devaluing, discounting, discrediting, and discriminating against these groups of people, play into and strengthen existing social inequalities—especially those of gender, sexuality, and race—that are at the root of HIV-related stigma.

Erving Goffman is widely credited for conceptualizing and creating a framework for the study of stigma. His work was seminal in creating an environment for ongoing academic research on the topic. In his landmark book *Stigma: Notes on the Management of Spoiled Identity* (1963), Goffman described stigma as “an attribute that is deeply discrediting within a particular social interaction” (p. 3). His explanation of stigma focuses on the public’s attitude toward a person who possesses an attribute that falls short of societal expectations. The person with the attribute is “reduced in our minds from a whole and usual person to a tainted, discounted one” (p. 3). Goffman further explained that stigma falls into three categories:

1. *Abominations of the body*—various physical deformities.
2. *Blemishes of individual character*—weak will, domineering or unnatural passions, treacherous and rigid beliefs, or dishonesty. Blemishes of character are inferred from, for example, mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicide attempts, or radical political behavior.
3. *Tribal stigma of race, nation, and religion*—beliefs that are transmitted through lineages and equally contaminate all members of a family (Goffman, 1963).

The stigma concept has been applied to myriad circumstances (Link and Phelan, 2001). Goffman’s ideas are a common thread in much of the published research and provide the theoretical underpinnings for much of the literature on stigma and stereotyping.

According to Goffman and other researchers, diseases associated with the highest degree of stigma share common attributes:

- + The person with the disease is seen as responsible for having the illness.
- + The disease is progressive and incurable.
- + The disease is not well understood among the public.
- + The symptoms cannot be concealed.

HIV infection fits the profile of a condition that carries a high level of stigmatization (Goffman, 1963; Herek, 1999; Jones et al., 1984). First, people infected with HIV are often blamed for their condition and many people believe HIV could be avoided if individuals made better moral decisions. Second, although HIV is treatable, it is nevertheless a progressive, incurable disease (Herek, 1999; Stoddard, 1994). Third, HIV transmission is poorly understood by some people in the general population, causing them to feel threatened by the mere presence of the disease. Finally, although asymptomatic HIV infection can often be concealed, the symptoms of HIV-related illness cannot. HIV-related symptoms may be considered repulsive, ugly, and disruptive to social interaction (Herek, 1999).

The discrimination and devaluation of identity associated with HIV-related stigma do not occur naturally. Rather, they are created by individuals and communities who, for the most part, generate the stigma as a response to their own fears. HIV-related stigma manifests itself in various ways. HIV-positive individuals, their loved ones, and even their caregivers are often subjected to rejection by their social circles and communities when they need support the most. They may be forced out of their homes, lose their jobs, or be subjected to violent assault. For these reasons, HIV-related stigma must be recognized and addressed as a life-altering phenomenon.

HIV-related stigma has been further divided into the following categories:

- + *Instrumental HIV-related stigma*—a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness (Herek, 1999)
 - + *Symbolic HIV-related stigma*—the use of HIV/AIDS to express attitudes toward the social groups or “lifestyles” perceived to be associated with the disease (Herek, 1999)
 - + *Courtesy HIV-related stigma*—stigmatization of people connected to the issue of HIV/AIDS or HIV-positive people (Snyder et al., 1999, based on Goffman, 1963).

Stigma and the General Population

Within the literature and within policy and care settings, much attention has been given to stigmatizing attitudes related to HIV/AIDS. Perhaps no contribution has been more significant than that of Gregory M. Herek, Ph.D., a professor of psychology at the University of California at Davis who is an internationally recognized authority on prejudice against lesbians and gay men, hate crimes and antigay violence, and HIV-related stigma. Herek's work frames much of the following discussion about stigma in the general population.

Herek (1990) observed that gay men and injection drug users are disproportionately susceptible to HIV-related stigma and discrimination. He has found that HIV-related stigma is not necessarily a stigma of the diseased; rather, it is often related to perceived lifestyle "choices" of infected populations or to perceptions about racial and ethnic minorities. In contrast, people who acquire HIV through no action of their own (for example, hemophiliacs and babies of HIV-positive women) have been referred to as "innocent" or "blameless."

Herek (1990) referred to previous studies that found that people with AIDS are evaluated more negatively than people diagnosed with other incurable diseases, even by health care workers. He also cited studies that found that it was common for caregivers to avoid people with AIDS and to overestimate the risks of casual contact with people living with HIV/AIDS.

HIV/AIDS-related stigma extends beyond individuals living with HIV/AIDS to volunteers, caregivers, co-workers, and professionals who provide HIV/AIDS services or advocacy. For example, some patients will

switch medical providers when they learn that their provider is HIV-positive or cares for HIV-positive patients. Herek and Capitanio (1997) referred to a study by Gerbert (1991b) showing that individuals who had direct contact with an HIV-positive person were less likely than those who had no contact with an HIV-positive person to switch health care providers on the basis of the HIV status of the provider or the provider's patients.

Herek and Capitanio (1993) found that HIV/AIDS-related stigma exists in a "significant minority" of the U.S. population. They used a 1991 random-digit telephone survey to examine stigmatizing attitudes about HIV/AIDS. Of the 1,145 households surveyed, 538 were defined as "Black" households. Responses differed little by race. The authors found that 27.1 percent of all participants gave a "stigmatizing response" when asked if they felt angry towards people with AIDS. When asked if people living with AIDS should be separated from the general population, 35.7 percent of the participants gave a stigmatizing response.

When participants in the 1991 telephone survey were asked if people with AIDS have "gotten what they deserved," 20.5 percent of White respondents and 16.5 percent of Black respondents said yes. Thirty-three percent of White respondents agreed that people with AIDS should be legally separated, or quarantined, compared with 40 percent of Black respondents. And 19.2 percent of White respondents said they would avoid a co-worker with AIDS, compared with 21.1 percent of Black respondents. White women were the least likely of any group surveyed to overestimate the risks of casual contact or to anticipate that they would avoid people with AIDS (Herek and Capitanio, 1993).

Herek and Capitanio conducted follow-up telephone surveys in 1992 and 1997, both of which used similar methodology. The authors documented what appeared to be increasing levels of stigma and a "hierarchy of blame" regarding HIV/AIDS (Herek and Capitanio, 1999). They wrote, "In our 1991 survey, for example, 20.5 percent of respondents agreed that 'people with AIDS have gotten what they deserve.' Approximately 6 years later, in the 1997 survey, 28.8 percent agreed with the statement, an increase of roughly 40 percent" (p. 1128). Even more of the 1997 respondents assigned some degree of responsibility when the question was framed less harshly. For example, 55.1 percent agreed that "most people with AIDS are responsible for their own illness" (Herek and Capitanio, 1999). The authors drew four major conclusions about HIV/AIDS-related stigma in the United States:

1. Most of the heterosexual adults who were surveyed equate AIDS with homosexuality or bisexuality and, in turn, harbor higher levels of prejudice.
2. Much of the public continues to label people with AIDS as blameworthy or innocent; moreover, among those who contracted AIDS through sexual activity, gay men are viewed more negatively than are heterosexuals.
3. Some portions of the public equate any same-sex behavior with AIDS; misconceptions and a lack of understanding about AIDS promote the view that all homosexual behavior eventually leads to AIDS.
4. A substantial portion of the public harbors exaggerated fears about "symbolic" contact with HIV-positive people, such as touching an article of clothing worn by a person living with HIV disease. These attitudes are most prevalent among people who harbor sexual prejudice (Herek and Capitanio, 1999).

Herek and Capitanio also examined the relationship between HIV-related stigma and direct or vicarious contact with people with AIDS. Study results indicated that contact with a person living with HIV disease reduced stigma and that such contact was more likely among relatively affluent individuals—those with at least some college and annual incomes greater than \$40,000 (Herek and Capitanio, 1997).

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HIV-Related Stigma in the United States: Prevalence and Trends, 1991–1999¹

Support for Coercive AIDS-Related Policies

Percentage responding “agree somewhat” or “strongly agree.”

	1991	1997	1999
People with AIDS should be legally separated from others to protect the public health.	34.4%	16.6%	12.0%
The names of people with AIDS should be made public so that others can avoid them.	28.8%	18.6%	16.3%
Women who are pregnant should be required to be tested for the AIDS virus in order to protect the health of their unborn baby.	N/A	83.0%	81.9%
People at risk for getting AIDS should be required to be tested regularly for the AIDS virus.	N/A	73.8%	63.5%
People from other countries who want to live in the United States should first be required to have an AIDS test to prove they are not infected with the AIDS virus.	N/A	77.5%	74.1%

Attributions of Responsibility and Blame for People With HIV/AIDS

Percentage responding “agree somewhat” or “strongly agree.”

	1991	1997	1999
People who got AIDS through sex or drug use have gotten what they deserve.	20.3%	28.1%	24.8%
Most people with AIDS don't care if they infect other people with the AIDS virus.	N/A	25.5%	21.8%
Most people with AIDS are responsible for having their illness.	N/A	53.5%	48.3%

Inaccurate Beliefs About HIV Transmission

Percentage of respondents incorrectly believing that the listed activity is “very likely,” “somewhat likely,” or “somewhat unlikely” to transmit AIDS. (The responses “very unlikely” and “impossible” were counted as correct responses).

	1991	1997	1999
Kissing someone on the cheek who has the AIDS virus.	17.1%	13.3%	N/A
Sharing a drink out of the same glass with someone who has the AIDS virus.	47.6%	53.2%	50.1%
Using public toilets.	34.0%	40.9%	40.8%

¹ All the data in this chart appeared in an article by G.M. Herek, et al. in 2002. Interviews for the 1997 and 1999 surveys were conducted by the Survey Research Center at the University of California at Berkeley, using its computer-assisted telephone interviewing system. The median duration of interviews was 44 minutes. For the 1997 survey, the sampling frame was the population of English-speaking adults (at least 18 years of age) residing in households with telephones within the 48 contiguous states. The sample was drawn using a list-assisted random-digit dialing (RDD) procedure. Interviews were fully or substantially completed with 1,309 respondents (a response rate of 65.1%). The 1999 survey was conducted with a new sample, using the same sampling frame and RDD procedure as the 1997 survey. Interviews were fully or substantially completed with 669 respondents (a response rate of 58%). Data from the 1997 and 1999 surveys were compared with findings from the research team's 1991 national telephone survey. The 1991 survey results presented use unweighted data and are based on that study's primary sample ($N = 538$), which was selected using a methodology comparable to that of the later surveys. More detailed information about the methodology is available in the original report.

Inaccurate Beliefs About HIV Transmission (continued)

	1991	1997	1999
Being coughed on or sneezed on by someone who has the AIDS virus.	45.7%	53.6%	50.4%
Donating or giving blood.	32.2%	28.9%	32.9%

“Exaggerated and Seemingly Irrational Fears” About HIV Contagion

Researchers measured respondents’ exaggerated fears about contracting HIV through “symbolic” contact with an object that had once been touched by a person with AIDS (PWA). This phenomenon has also been described as “belief in the magical law of contagion.”

	1991	1997	1999
Less likely to wear sweater once worn by a PWA. ²	N/A	26.8%	25.7%
Uncomfortable about drinking out of a washed, sterilized glass in a restaurant that had been used a few days earlier by a PWA. ³	N/A	26.9%	25.7%

Discomfort and Avoidance of Contact With People With HIV/AIDS

	1991	1997	1999
Suppose you had a young child who was attending school where one of the students was known to have AIDS.			
Percentage who would feel “somewhat” or “very” uncomfortable.	N/A	26.6%	30.3%
Percentage who would avoid person with AIDS.	14.9%	9.9%	8.5%
Suppose you worked in an office where one of the men working with you developed AIDS.			
Percentage who would feel “somewhat” or “very” uncomfortable.	N/A	24.7%	22.4%
Percentage who would avoid person with AIDS.	18.6%	11.7%	9.1%
Suppose you found out that the owner of a small neighborhood grocery store where you liked to shop had AIDS.			
Percentage who would feel “somewhat” or “very” uncomfortable.	N/A	28.6%	27.2%
Percentage who would avoid person with AIDS.	45.2%	32.2%	29.3%

² Percentage whose self-rated likelihood of wearing sweater worn by a PWA was lower than previously rated likelihood of wearing another sweater. Respondents were asked about their willingness to wear “a very nice sweater that had been worn once by another person who you didn’t know” and had been “cleaned and sealed in a new plastic package so that it looked like it was brand new.” Respondents were then asked about the likelihood that they would wear the same sweater if they “found out that the person who had worn it the one time before had AIDS.”

³ Percentage who would feel “not very comfortable” or “not at all comfortable” about drinking out of a washed, sterilized glass used a few days earlier by a PWA.

Source: Herek GM, Capitanio JP, Widaman KF. HIV-related stigma and knowledge in the United States: prevalence and trends, 1991–1999. *Am J Public Health*. 2002;92(3):371–7. Available at: <http://psychology.ucdavis.edu/rainbow/html/ajph2002.pdf>.

There is some evidence that HIV/AIDS-related stigma declined over the 1990s. For example, in 2000, the CDC published results from a study of 5,641 people in which 18.1 percent of participants gave a response suggesting that they harbor stigmatizing attitudes toward HIV-positive individuals. Herek et al. (2002) described findings from their 1999 telephone survey that also indicate that some expressions of stigma declined over the 1990s. The proportion of people advocating the most drastic measures—quarantine and public identification—significantly diminished. However, although most people surveyed understood how AIDS is transmitted, they were less clear on how AIDS is *not* transmitted. And despite reductions in stigma, one-fifth of those surveyed feared people with AIDS, and one-fourth felt uncomfortable having contact with people with AIDS. Another result underlines the power of stigma to extend to the economic realm: Nearly one-third of respondents said that they would avoid shopping at a neighborhood grocery known to be owned by a person with AIDS.

Other studies have tried to better define populations that harbor HIV-related stigma and that may practice discrimination. Rozin et al. (1994) cited a study that reported an association between fear of AIDS and regular church attendance. Herek and Capitanio (1998) found that 41 percent of heterosexual adults based their HIV-related attitudes on religious or political values; only 13 percent based their attitudes on concerns for personal safety. Herek (1999) cited several studies finding that younger and more highly educated people typically manifest lower levels of HIV-related stigma than do older people and those who are less educated.

Stigma and Access to Care

The literature devoted to stigma and access to care falls roughly into three categories. Most of the literature deals with barriers to care that HIV-positive individuals encounter across the continuum from HIV diagnosis to end of life. The next largest category of studies documents the reluctance of health care providers to treat individuals with HIV infection. Finally, a few studies cover the stigma experienced by providers of ancillary and support services to people living with HIV/AIDS.

Individuals

HIV/AIDS-related stigma affects issues related to HIV testing, including delays in testing, the effect of delay on further transmission of HIV, and individuals' responses to testing positive (Chesney and Smith, 1999). Early detection of HIV infection is important. Knowledge of one's HIV seropositivity can lead to earlier treatment and improved outcomes (Herek, 1990). Knowledge of seropositivity also can lead to changes in behavior that can reduce or eliminate the risk of HIV transmission.

A Kaiser Health Poll Report (2000) suggested that fear of being stigmatized by HIV/AIDS has some relationship to people's decisions about getting tested for HIV. One-third of survey respondents said that if they were tested for HIV, they would be "very" or "somewhat" concerned that people would think less of them if they discovered that they had been tested. In addition, 8 percent of people who had never been tested for HIV said that worries about confidentiality played a part in their decision not to have the test.

Studies provide evidence that stigma is associated with delays in HIV testing among individuals who are at high risk of being infected with HIV (Myers et al., 1993; Stall et al., 1996). In a study of gay and bisexual men who were unaware of their HIV status, two-thirds of the participants expressed a fear of discrimination against people with HIV and said it was a reason for not getting tested (Stall et al., 1996).



Earlier in the epidemic, HIV stigmatization was shown to influence the way in which at-risk populations approached HIV testing. People at risk for HIV infection were more likely to seek testing that was offered anonymously (i.e., no names were recorded) than testing that was offered confidentially (i.e., names were kept in confidential files) (Fehrs et al., 1988; Johnson et al., 1988).

HIV/AIDS-related stigma also influences individuals' responses to testing positive: It aggravates the psychological burden of receiving a positive HIV test result (Chesney and Smith, 1999). Earlier in the epidemic, there were reports of severe psychological responses to notification, including denial, anxiety, depression, and suicidal ideation (Coates et al., 1987; Ostrow et al., 1989). Over time, studies have shown a decrease in severe reactions to being notified of positive test results; however, research continues to show that notification is associated with high distress. Distress is greatest immediately after notification and typically declines within 2 to 10 weeks (Ironson et al., 1990; Perry et al., 1990).

Stigma also affects the care of HIV-positive individuals. After a person tests positive, he or she faces decisions that include how to enter and adhere to care and whether to disclose HIV seropositivity to partners, friends, family, colleagues, employers, and health care providers (Chesney and Smith, 1999). At each level, a decision to disclose seropositivity may either enhance access to support and care or expose the individual to stigmatization and potential discrimination.

Health Care Providers

Accessing health care can be a challenge for people who are HIV positive, because the health care system itself is often a source of stigma. Health care professionals, particularly those who infrequently encounter HIV-positive people, can be insensitive to their patients' concerns about stigma. In addition, health care professionals are not always knowledgeable about appropriate procedures for maintaining patient confidentiality (Herek et al., 1998).

The literature on caregiving reveals that stigmatization is evident among health care providers. Fear of infection and fear of death have clear negative effects on health care providers' attitudes toward and treatment of HIV-positive patients (Gerbert et al., 1991a; Weinberger et al., 1992).

Health care providers also may fear stigmatization themselves because of their work with HIV-positive patients (Durham, 1994). Caregivers, whether professionals or volunteers, risk what Goffman called "courtesy stigma," in which they are stigmatized as a result of their association with HIV/AIDS and people living with HIV disease. That stigma may influence their willingness to work with people with HIV or may make their work more difficult (Snyder et al., 1999).

Providers of Ancillary and Support Services

Throughout the course of the HIV/AIDS epidemic, volunteers have been important participants in the nationwide response to the disease. Volunteers have worked to educate the public about HIV transmission and prevention, provided assistance to people living with HIV, donated money and resources to organizations that provide care and treatment for people living with HIV, and raised funds for research on treatment for HIV (Snyder et al., 1999).

Snyder et al. (1999) discussed stigmatization as a barrier to HIV/AIDS volunteerism and noted the power of stigma to actually punish volunteers for their good deeds. Like health care workers, HIV/AIDS volunteers may experience courtesy stigma.

Research reveals that volunteers and nonvolunteers consider HIV/AIDS volunteerism more stigmatizing than other forms of volunteerism (Snyder et al., 1999). Reports of having been made to feel embarrassed, stigmatized, or otherwise uncomfortable in connection with their volunteer activities are more common among HIV/AIDS volunteers than other types of volunteers (Omoto et al., 1998). Volunteers who had been unexpectedly stigmatized reported being less satisfied and more burned out than volunteers who expected to be stigmatized (Snyder et al., 1999). Reports of actual stigmatization predicted HIV/AIDS volunteers' burnout from their work and hastened their decision to quit (Snyder et al., 1999).

One study hypothesized that volunteers' association with HIV/AIDS and with people living with the disease is responsible for their feelings of stigmatization (Snyder et al., 1999). Findings support the hypothesis that potential volunteers perceive HIV/AIDS volunteer work to be different and more stigmatizing than cancer volunteer work (Snyder et al., 1999). Potential stigmatization also prevents nonvolunteers from helping AIDS organizations.

Violence

Violence, defined here as physical assault, is common in the United States. Although men are victims of violent crime more often than women are, women are 5 to 8 times more likely to be victims of assault in the context of intimate relationships. Studies indicate that the epidemiology of physical assault within personal relationships mirrors the epidemiology of HIV infection in women. Risk factors include poverty, unemployment, drug use, childhood sexual and physical abuse, being younger than 30 years old, and homelessness (Zierler et al., 1996; Zierler and Krieger, 1997).

Hate crimes are criminal actions intended to harm or intimidate people because of their race, ethnicity, sexual orientation, religion, or other minority group status (Herek et al., 1999).

Most women living with HIV—as well as those at highest risk for HIV infection—are poor and members of a minority group. They suffer violence throughout their lives that is beyond what women of higher socio-economic status generally experience. This background of violence, along with poverty, drug use, and the burden of caring for themselves and others, creates a number of potential obstacles or barriers to care for HIV disease and coexisting conditions (Vlahov et al., 1998).

The literature indicates that violence and HIV/AIDS may be linked in other ways. Some researchers have suggested that disclosure of HIV positivity may provoke violence in intimate relationships (Gielen et al., 1997; Zierler, 1997).

One study examined the proportion of HIV-positive adults who had been assaulted since their HIV diagnosis by a partner or someone important to them and the extent to which they reported their HIV-positive status

as a cause of the violence (Zierler et al., 2000). Participants were a nationally representative probability sample of 2,864 HIV-positive adults who were receiving medical care and were enrolled in the HIV Costs and Service Utilization Study. A total of 20.5 percent of the women, 11.5 percent of the men who reported having sex with men, and 7.5 percent of the heterosexual men said they had experienced physical harm since HIV diagnosis. Nearly half of that group reported HIV seropositive status as a cause of violent episodes. Factors most strongly associated with partner and relationship violence were drug dependence, homelessness, and unemployment. It follows that HIV prevention and treatment programs are appropriate settings for violence assessment and sexual assault counseling services for women and men living with or at risk for HIV infection (Vlahov et al., 1998; Zierler et al., 2000).

HIV-related stigma may contribute to victimization based on sexual orientation. Men are at higher risk for victimization than women, and people who are open about their sexual orientation are at higher risk than people who try to conceal their sexual orientation (Herek et al., 1998). People who identify themselves as gay, lesbian, or bisexual and others who are at risk for HIV may experience extreme stigma in the form of hate crimes.

Hate crimes have been defined as criminal actions intended to harm or intimidate people because of their race, ethnicity, sexual orientation, religion, or other minority group status (Herek et al., 1999). Survivors of hate crimes that are based on sexual orientation are more likely than other respondents are to regard the world as unsafe. Survivors may also view people as malevolent and may experience personal setbacks.

Research findings support the hypothesis that experiencing hate crimes links the victim's feelings of vulnerability and powerlessness with his or her sexual orientation and personal identity (Herek et al., 1999). Victims may believe that their sexual orientation puts them at a higher risk for all kinds of negative experiences. Victims of hate crimes based on sexual orientation have been found to suffer greater psychological distress than victims of non-bias-related crimes (Herek et al., 1998).

Interventions

HIV/AIDS-related stigma affects self-esteem, mental health, access to care, providers' willingness to treat people with HIV, violence, and HIV incidence. Interventions to reduce stigma are therefore crucial for improving care, quality of life, and emotional health for people living with HIV and AIDS. HIV/AIDS-related stigma has been specifically identified as a domestic policy challenge that must be addressed to reduce the number of new HIV infections, and eliminating stigma is a crucial element of global efforts (Institute of Medicine, 2001; Joint United Nations Programme on HIV/AIDS [UNAIDS], 2001; Henry J. Kaiser Family Foundation, 2002; Klein et al., 2002).

The importance of this issue is highlighted in the UNAIDS publication *A Conceptual Framework and Basis for Action: HIV/AIDS Stigma and Discrimination* (2002). The document describes several interventions in the international arena but laments the shortage of documented efforts to challenge HIV/AIDS-related stigma. This deficit is also noted by Brown, Trujillo, and Macintyre (2001), who wrote, "Given the magnitude of this pandemic one could hardly claim that the area of stigma reduction is well studied" (p. 15).

The literature on interventions and HIV-related stigma can be divided into three categories: statutory and regulatory, policy development, and programs and services. Most of the literature deals with the legal area.

Considerably less attention has been devoted to programmatic interventions, which attempt to change attitudes and behavior. However, a multifaceted approach that goes beyond legal protections is necessary to address the social climate that sometimes appears to legitimize discrimination (Klein et al., 2002).

Legal and Policy Interventions

In the early years of the epidemic, a consensus emerged among public health officials to approach AIDS differently from other infectious diseases and sexually transmitted infections. Public health officials wanted to avoid stigma and mistreatment that could “drive the epidemic underground,” which would compromise access to care and services, deter or delay HIV testing, and undermine the effectiveness of HIV prevention efforts (Bayer, 1999; Burris, 1999). Prevention measures that were noncoercive and that respected the privacy and social rights of those who were at risk were used. Because no treatment for HIV/AIDS existed at the time, mass education, voluntary testing, and counseling were key elements in this public health strategy (Bayer, 1999; Burris, 1999).

Despite public health officials’ approach to the AIDS epidemic, their efforts did not prevent HIV/AIDS-related discrimination. People living with HIV, as well as people who are merely believed to be HIV positive, have been fired from their jobs, evicted from their homes, and denied services. Discrimination has occurred despite legal precedents and protective legislation. It has been reported in the areas of employment, health care, insurance, and education. Ironically, some institutional policies and laws designed to protect people with HIV from stigma can help perpetuate it. For example, privacy laws assist HIV-positive people with managing stigma, but they may also contribute to the characterization of AIDS as a dirty little secret (Herek et al., 1998).

Law and legal protections are essential components of the societal response to stigma and discrimination (Klein et al., 2002). The recognition of the negative consequences of HIV/AIDS stigma, for individuals as well as for the public health, led to the enactment of statutory protections for people living with HIV disease. The confidentiality of HIV-related information, particularly HIV test results, enjoys considerable protection under State laws and the U.S. Constitution (Burris, 1999).

The 1990 Americans with Disabilities Act (ADA) expanded the reach of the Rehabilitation Act of 1973 and made discrimination on the basis of disability unlawful. In *Bragdon v. Abbot* (1998), the first discrimination case involving HIV infection or AIDS to reach the Supreme Court, the Court ruled that Congress intended HIV infection to be included as a disability under the ADA (Annas, 1998). HIV infection has been found to meet the definition of disability under Federal and State laws protecting people with disabilities from discrimination in employment, housing, government services, and public accommodations such as hotels, schools, and medical offices (Burris, 1999).

Along with legal protection from discrimination on the basis of HIV status, HIV was exempted from traditional public health practices, such as contact tracing and partner notification. Although AIDS is a reportable disease in all 50 States, requirements for reporting HIV infection vary from one State to another. This pattern led to the coining of the term “HIV exceptionalism” to distinguish the policies that emerged in the face of the AIDS epidemic from more conventional approaches to public health threats (Bayer, 1999). Support for HIV exceptionalism has diminished in recent years as more effective therapies have been developed for

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Practical Steps to Prevent HIV-Related Stigma and Discrimination: A Checklist for Public Health Practitioners

Statutory/Regulatory Environment

- + Familiarize yourself with applicable laws and regulations in your jurisdiction.
 - + Initiate or support actions to advance or strengthen protection.

Policy Development

- + Involve consumers in program design, development, and evaluation of programs and policies.
 - + Support and engage other agencies in promoting confidentiality and nondiscrimination.
 - + Promote community development and mobilization.

Program and Services

- + Use public education opportunities to put a human face on AIDS.
 - Involve people living with HIV/AIDS in public education.
 - Show the diversity of the epidemic.
 - + Support HIV prevention education materials developed by and for communities.
 - + Maintain a proactive presence in the community (e.g., in schools, at health fairs, at World AIDS Day, and at National HIV Testing Day events).
 - + Involve and support families and communities (infected and affected).
 - + Engage leaders from the business community and faith communities (e.g., “Business and Labor Respond to AIDS,” Faith Forums, Black Church Week of Prayer).
 - + Develop and implement training, policies, and procedures for all staff activities and programs.
 - + Integrate within contracts relevant provisions for prevention, care, and supportive services.
 - + Seek, value, and support a staff reflective of the diversity of communities.
 - + Provide training and technical assistance on confidentiality, nondiscrimination, and cultural diversity to staff, contractors, and other health and human service providers.
 - + Educate clinicians so that they are not reluctant to treat people living with or at risk of HIV/AIDS.
 - + Ensure access to confidential and anonymous HIV testing.
 - + Integrate HIV prevention into primary care.
 - + Integrate primary and secondary prevention.
 - + Communicate that HIV-related discrimination is illegal.
 - Support and promote legal services for consumers.
 - Remain cognizant of issues related to social isolation and stigma in rural areas.
 - Identify and support one or more staff members in the role of consumer advocate.
 - Implement policies and procedures for complaints.
 - Follow through on enforcement.

Source: Klein SJ, et al. Interventions to prevent HIV-related stigma and discrimination: findings and recommendations for public health practice. *J Public Health Manag Pract.* 2002;8(6):44-53.

HIV disease and as the belief that HIV-related stigma has diminished substantially has become more widespread (Bayer, 1999; Herek, 1999). Bayer noted:

The advances of medicine have served to undermine the exceptionalism of the HIV epidemic's first years in America. Practices uniquely informed by a commitment to privacy rights are increasingly vulnerable to challenge as despair and therapeutic impotence give way to a (perhaps premature) therapeutic triumphalism. . . . That the era of exceptionalism may be coming to a close is, thus, not the end of the story. The privacy interests of persons infected with HIV require a basic encounter with the role and limits of medical privacy, more generally, just as the need for HIV care requires a confrontation with the broader question of justice in the American health care system (Bayer, 1999: p. 158).

For maximum impact, policy and legal interventions to prevent HIV must be integrated with interventions against HIV-related stigma and discrimination. Legal protections are essential components of the societal response to stigma and discrimination (Klein et al., 2002). Public health practitioners must be aware of the specific statutory and regulatory framework of their States so that policy and program development occurs within existing legal protections against stigma and discrimination (Klein et al., 2002).

Program and Service Interventions

One review of the literature analyzed 21 studies from developed and developing countries in terms of the types of interventions used to decrease HIV-related stigma. Only eight of the studies were conducted in the United States (Brown et al., 2001). The studies reviewed show that stigma can be reduced through a variety of intervention strategies, including the following:

- + *Information.* Information can be delivered by advertisements, brochures, information packs, classes, or lecture presentations. This approach frequently includes a factual description of the disease along with details on modes of transmission and methods of risk reduction.
- + *Counseling.* Information-based approaches are often combined with counseling (e.g., support groups for people living with HIV/AIDS). This strategy provides praise and social support for positive attitudes, behavior change, and maintenance of safe behaviors. Participants receive personal support for resolving issues with spouses, partners, families, and others in a safe environment.
- + *Coping skills acquisition.* Master imagery and group desensitization are two techniques for teaching coping skills. In master imagery, a person is presented with a hypothetical situation in which he or she has contact with an HIV-positive person and is taught appropriate coping skills for resolving the situation. Group desensitization begins with relaxation training and then progressively exposes the individual or group to a number of situations involving people living with HIV/AIDS. Participants use the newly learned relaxation techniques to decrease tension in a hypothetical situation.
- + *Contact.* Contact with HIV-infected or HIV-affected individuals is used alone or in combination with other strategies. Contact can create an environment in which the general population can interact with members of the stigmatized group, either directly or vicariously (e.g., through the media). The theory is that more personal contact with an HIV-positive person will demystify and dispel misinformation and generate empathy and, in turn, reduce stigma and prejudice. This contact can range from face-to-face conversations to hearing testimonials from HIV-infected or HIV-affected persons.

The stigma reduction interventions described above appear to work. However, most of the interventions were tested on small numbers of subjects. In addition, few studies looked at whether changes in attitudes and behaviors were sustained over time (Brown et al., 2001, 2003).

Interventions to prevent HIV-related stigma and discrimination are integral components of the comprehensive approach to HIV/AIDS described by the New York State Department of Health AIDS Institute (Klein et al., 2002). The AIDS Institute provides programs and services in applied settings, including training for clinical and nonclinical providers, consumer education, social marketing approaches for communitywide education and awareness, and support for consumer complaints.

For example, the AIDS Institute offers free training and clinical education programs that address prevention of stigma and discrimination. The programs take place at locations throughout the State. Topics include the HIV/AIDS Confidentiality Law (Article 27-F), cultural diversity, domestic violence, HIV testing procedures, HIV reporting and partner notification, gender identity and expression in communities of color, and treatment education. The New York State Targeted Provider Education Demonstration Program, funded by HRSA/HAB, builds capacity in minority organizations for education and training of health and human services providers.

Another example is the promotion of consumer education, empowerment, and advocacy. The AIDS Institute promotes and funds interventions that address consumer education and skills building. In partnership with the New York City Department of Health, the AIDS Institute has funded and assisted in developing the People Living with HIV/AIDS Leadership Training Institute (LTI). The LTI promotes skills building, community leadership, and self-empowerment in an experiential environment and has trained more than 700 people living with HIV/AIDS as community leaders and resources. LTI graduates serve on community advisory boards, Ryan White Title II consortia, Title I planning councils, and HIV prevention planning groups. Participants report increased self-confidence and feelings of empowerment.

Afterword
July 2004

Since the development of *Stigma and HIV/AIDS: A Review of the Literature* in May 2003, we have continued to monitor articles on HIV-related stigma published in major journals. Our latest search focused on the domestic epidemic and included materials published from May 2003 through June 2004. The results yielded 23 articles of prime importance, including the section on stigma and discrimination in the December 2003 *UNAIDS Epidemic Update*. A bibliography is provided below.

Consistent with our earlier findings, most of the 23 articles dealt with the evolution of HIV-related stigma and with policy and legal initiatives for addressing stigma. Much less material has been published on programmatic solutions. In fact, none of the reports focused specifically on stigma interventions.

As researchers continue to try to better understand HIV/AIDS among certain populations, more are recognizing that stigma is a barrier to sustained care, and they are finding that stigma influences the extent to which some HIV-affected populations seek and use prevention, education, and related intervention services. For example, 5 of the 23 articles addressed HIV issues faced by women; specifically, mothers. The researchers found that the stigma related to maternal HIV disclosure to children and other family members, combined with the complexity of treatment regimens, limited access to care, and disparities in health, posed huge barriers to care for women, most of whom have children to care for. Other articles focused on men

who have sex with men, HIV-positive individuals over age 50, the role of religion, complimentary and alternative therapies, HIV counseling and testing, and the stigma associated with HIV co-infections and sexually transmitted infections.

The most recent research indicates that HIV-related stigma is relevant regardless of HIV status. Stigma, fear, and anger were identified by many members of all populations, including those who are HIV positive, those at risk for HIV, and those who do not know their HIV status. Perhaps most compelling is the need to address the stigma attached to HIV counseling and testing. The research indicates that a critical issue is the effect of HIV-related stigma on the willingness to be tested. HIV stigma compounded by stigma about race, age, sexual orientation, and other issues is an increased deterrent to testing.

The well-being of people who are HIV-positive or are at risk for HIV is compromised by the stigma that is attached to all facets of infectious disease. It is imperative that those who provide services to people who are infected with or affected by HIV continue to try to mitigate all forms of stigma, especially stigma that prevents people from seeking proper medical and psychological care during the early stages of disease. The literature on HIV-related stigma provides an idea of the scope of HIV-related stigma and its consequences for those who serve people in need. It also gives health care providers ideas of what is needed to effectively combat stigma. However, the relative shortage of literature on HIV-related stigma interventions is a reminder that we have far to go before the issues surrounding stigma are no longer relevant for those in need of care. As providers continue to evaluate and measure the effectiveness of activities that specifically target stigma, it is hoped that an increasing body of literature will develop that provides practical steps for mitigating the force of stigma.

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